



LIVING WITH DIGNITY

Bill 11

An Act to amend the Act Respecting End-of-Life Care
and other legislative provisions

**The frontiers of incapacity, disability,
and institutional constraint**

**Brief submitted by the
Living with Dignity citizen network**

Presented to the Committee on Citizen Relations

March 28, 2023

Presentation of the Living with Dignity citizen network



Living with Dignity is a non-profit Quebec citizen network based in Quebec, with no religious or political affiliation. It was incorporated in Montreal on May 19, 2010.

Vision

We believe in a society where everyone can live in dignity, with the certainty that their life is valued, regardless of their state of health. We aim to build a solidarity-based society that ensures its citizens a natural and respectful end of life.

Mission

Promote the protection of life, inherent dignity and support for people made vulnerable due to illness, old age or disability.

Over the years, nearly 20,000 people, primarily from Quebec, have signed our manifesto:

vivedignite.org/a-propos/declaration

This is the fourth brief submitted to the National Assembly of Quebec.

The first three were submitted to:

- The Select Committee on Dying with Dignity, August 18, 2010;
- The Committee on Health and Social Services (Bill 52), September 25, 2013;
- The Select Committee on the Evolution of the Act Respecting End-of-Life Care, August 6, 2021.

Introduction

Medical aid in dying in Quebec Where to draw the line?

Bill 11 suggests further expansion of access to medical aid in dying in Quebec. In this context, why consider the point of view of a group opposed to medical aid in dying in all circumstances?

We work in a spirit of cooperation with groups and individuals who do not always share our views but who oppose or criticize some of the expansions to the law. Since each frontier of access to medical aid in dying brings its share of new ethical and moral issues, we believe it is important to speak out to express the deep convictions that drive our citizen network. To summarize our point of view, we often recall in our exchanges that there is always a better solution than euthanasia, called medical aid in dying (MAiD) in Quebec since 2015. With all due respect, we disagree with the MAiD = care assumption, as we did on the first day. In February, we were pleased to read the ethical opinion of 13 French organizations representing 800,000 health professionals entitled, *Can giving death be considered as care?*¹

Behind the often-idealized image of MAiD lie complex realities that emerge over time. This reality is most vividly depicted in the British Columbia case of Jennyfer Hatch. Quebecers got to know her through the spectacular All is Beauty ad campaign by La Maison Simons. Without disclosing her physical condition, the ad campaign sumptuously depicted her final days before "seeking help to end [her] life". We later learned that she had received MAiD on October 23, 2022, at the age of 37 (we reiterate our condolences to her loved ones). Few people knew that Ms. Hatch testified anonymously in June 2022 about her desire to live and the lack of access to appropriate care for living with Ehlers-Danlos syndrome, a rare genetic condition.²

We receive several testimonies from people who, out of respect for a loved one's decision to choose MAiD, are afraid to express their discomfort with this decision, its context, and the absence of better or more readily available quality palliative care that might have been suggested upstream. We are only beginning to notice the societal effects of medical aid in dying, which is not just a personal choice. Before crossing new frontiers in access to MAiD, we appreciate you taking the time to read our observations and recommendations, written from the heart on behalf of the people most at risk for the abuses we seek to prevent, just as you do.

Sincerely,

Alex King
President

Jasmin Lemieux-Lefebvre
Coordinator

¹<https://sfap.org/actualite/l-euthanasie-et-le-suicide-assiste-ne-peuvent-pas-etre-consideres-comme-des-soins>

²Full report available on our website: <https://vivredignite.org/elle-voulait-vivre-recit-jennyfer-hatch>

2–The frontier of incapacity

The bill allows persons suffering from a serious and incurable illness leading to incapacity to give consent to care to make an advance request for medical aid in dying so that they can receive such aid once they have become incapable.

Excerpt from the Explanatory Notes to Bill 11

At the heart of Bill 11, advance requests for medical aid in dying when a neurocognitive disorder leads to loss of capacity to consent seem to enjoy strong support:

- very high level of public support;
- recommendation of the Select Committee on the Evolution of End-of-Life Care.

Considering this reality, the Committee on Citizen Relations did not deem it pertinent to invite a single opponent to this specific expansion during the public hearings studying Bill 11. Of course, concerns have been raised, such as not allowing MAiD access to patients who do not exhibit signs of suffering, a condition known as happy dementia.

We will not repeat here what Quebec geriatricians have already expressed in their brief. We encourage readers to learn about these considerations:

- [Projet de Loi 11 - une erreur de prévision par un législateur idéaliste](#)
by Dr. Félix Pageau
- [L'aide médicale à mourir par demande anticipée](#)
by Drs José A. Morais, Pierre J. Durand, Donald M. Doell and Catherine Ferrier

We thank these geriatricians for giving us permission to share their briefs on our website.

The limits of advance and substituted consent, the numerous issues with the applicability of MAiD administration, potential conflicts of interest (many instances of elder abuse and neglect), and the significant effects of this new access on an already precarious network of geriatric care call into question the necessity of this expansion, which we also believe to be laced with ableism.

It should be noted that the geriatricians consulted claim that it is impossible to predict a person's level of well-being after they have experienced cognitive loss.

Our succinct brief will cover a topic not often mentioned, but which in our opinion is particularly crucial...

The therapeutic lie: at the heart of advance requests

Since the beginning of parliamentary proceedings, the notions of refusal and resistance to the administration of MAiD on the part of a person who has become incapable have often come up in discussions. In reality, it is unlikely that there will ever be any opposition or refusal. The drugs might be given covertly to prevent rejection reactions, as suggested by the Supreme Court of the Netherlands in April 2020.³The parliamentarians' noble intention to give a final opportunity for refusal would therefore not be applicable in practice.

Every step that leads to providing medical aid in dying to people incapable of giving consent will present several extremely difficult moral and ethical dilemmas. We will focus on two of them.

1) The trusted third party or competent personnel initiates the MAiD review process by advance request

As expressed in the bill in article 29.14, it is the observation of any of the following forms of suffering that will activate this process:

- a) the suffering described in the patient's request;
- b) persistent and unbearable physical or mental suffering that cannot be alleviated under conditions considered tolerable.

This measure is directly opposed to what is mandated during the professional's examination, i.e., observing the two types of suffering when MAiD is administered (second paragraph of article 29.18 of the proposed legislation). A difference that could lead to misunderstanding and unmet expectations...

Several voices can be heard in support of not limiting the possible suffering described in an advance request, in the name of the primacy of self-determination. When this suffering does not meet the criteria specified in (b) during an examination, relatives may be taken aback. Although these criteria are intended to prevent MAiD in cases of happy dementia, we are worried that they are insufficient. Some doctors have stated unequivocally that they do not believe in the idea of happy dementia, believing that it always conceals psychological suffering. The number of these physicians is such that the safeguard of the second competent professional to avoid the administration of MAiD in such conditions is challenging. We are also worried that the self-declaration system of the Committee on end-of-life care will not allow for the identification of these instances of abuse.

³Brief presented by Professor Trudo Lemmens to the Federal Joint Committee on Medical Aid in Dying.
<https://www.ourcommons.ca/Content/Committee/441/AMAD/Brief/BR11765215/br-external/LemmensTrudo-10616937-002-f.pdf>

If he persists in this avenue, the legislator should clearly express the “a” sufferings (described in a request) which can never be admissible as “b” sufferings. Moving to a residence, non-recognition of a loved one, a need for help with eating, dressing, or bathing, incontinence (and so on) should never be considered by society to be criteria for MAiD eligibility. This may seem obvious to many, but numerous Quebecers appear to be convinced they should be, and there has been a lack of strong reactions from political decision-makers when such ideas are floated in public. Look at the numerous comments about this topic on social media. Expanding access to MAiD always tacitly places a degrading institutional judgment on the value of individual human lives and reinforces vulnerable people's negative views of their own lives.

It should be noted that the trusted third party's duty to report that the patient has reached the situation in which he refused to live, and for which he had made an advance request, places an unfair burden on this person. This burden will grow heavier as time passes and the situation becomes more complicated. The choice to begin the examination for medical aid in dying is made by that third party.

2) If the request meets all the criteria of the law, the date and time of the MAiD will be determined

Some patients will have expressed the desire to be alone. **Difficulties to be expected for loved ones.** Some relatives will choose to be present if possible. They will be unable to discuss medical aid in dying with the incapable individual because the latter will not understand. **Difficulties to be expected for loved ones.** Even if they could, some family members will choose not to be present, unable to accept that their father, sister, or friend will be given medical aid in dying without realizing it. **Difficulties to be expected for loved ones.**

Regardless of the scenario, since MAiD will be founded on a therapeutic lie, the emotional burden borne by the health care team and any loved ones who may be present should be enough to discourage access to MAiD in this situation. Let us recall the very harsh words of a Dutch doctor on this subject, quoted on March 17 by columnist Katia Gagnon on 98.5 FM:

It is unbearable, according to Dr. Keizer, who has nevertheless performed euthanasia himself. Pardon the expression, but you will have to kill someone who no longer understands what is happening to them!⁴

Advance consent is not true consent. Teams administering MAiD to incapable individuals will eventually understand this.

⁴*L'euthanasie aux Pays-Bas, une façon normale de mourir*, 2017, News report by CBC
<https://ici.radio-canada.ca/nouvelle/1057242/euthanasie-pays-bas-normal-mourir-demence>

Implications for our vision of humanity

We also reject the anthropologic vision underlying advanced requests. The person living with dementia, in our opinion, is and remains a full human being, endowed with the indisputable human worth of each of us. If we believe that the autonomy of the person still capable of consenting trumps the will of the person with dementia, we are devaluing that person; this can have far-reaching implications for how we treat incapable adults.

Our recommendation 1: Rather than crossing the line of incapacity to access medical aid in dying, it would be preferable to invest extensively in geriatric care and support for people living with a neurocognitive disorder. By implementing best practices to treat the symptoms of illnesses and accompany the loss of capacity, they no longer need to fear being deprived of their dignity.

We also recommend listening to the podcasts *Devenir Margot*

<https://baladodiffusion.telequebec.tv/27/devenir-margot>

and *Devenir Roger*

<https://baladodiffusion.telequebec.tv/36/devenir-roger>

to better support people living with a neurocognitive disorder (available in French only).

3- The frontier of disability

(The bill) withdraws the end-of-life criterion from the criteria a person must meet to obtain medical aid in dying.

Excerpt from the Explanatory Notes to Bill 11

Our first argument is the surprising absence of any reference to disability in the bill's explanatory notes. It is critical to explicitly mention what is being considered, as we prepare to repeat in Quebec the errors made since Bill C-7 came into effect in Canada.

Given the almost complete absence of media coverage in Quebec, few observers here are aware that national organizations representing people with disabilities in Canada are almost unanimously opposed to MAiD access directly targeting disability. [This was true before Bill C-7 was passed in March 2021 and](#) is still true today. We echo the words of Inclusion Canada in their brief last year to the Special Federal Joint Committee on Physician-Assisted Dying (AMAD):

The only way to ensure the “protection of persons with disabilities” is to stop exceptionalizing their suffering, to reinstate an end-of-life requirement in the law, and to alleviate the structural and systemic conditions that make life intolerable for so many persons with disabilities.⁵

Abuses that should cause us to exercise extreme caution

Several groups have documented cases of abuse in the administration of medical aid in dying to people with disabilities who are not nearing the end of their lives. On our website, we identified several of these high-profile cases:

<https://vivredignite.org/revue-de-presse-derives-nouveaux-acces-amm>

The episode "The Mess that is MAiD" of CBC's Fifth Estate allows for a clear understanding of the obvious issues associated with this expansion: <https://youtu.be/plinQAHZRvk> (For example, in Ontario, Kiano Vafaeian, 23 years old, diabetic and blind, was approved for a September 2022 MAiD appointment before changing his mind, thanks to his family's support).

Too often, people with disabilities struggle to obtain the care they need or live in precarious socio-economic conditions. In these cases, requests for medical aid in dying are the fruit of frustration. The safeguards in place in Canada should protect vulnerable people from these abuses, but requests are accepted because psychological and existential distress is so broadly defined.

⁵The Protection of Persons with Disabilities, brief submitted by Inclusion Canada to AMAD Committee [InclusionCanada-e.pdf \(ourcommons.ca\)](#)

While preparing this brief, we sought the wisdom of Ms. Louise Brissette, physiotherapist and mother of 37 disabled children whom she adopted over the past 40 years. Founder of the [Œuvre des Enfants d'amour](#) and recipient of several well-deserved recognitions,⁶ she says:

"We no longer choose life with all that it has to offer in terms of beauty, goodness, and truth, as well as difficulties that help us go further and find true love, the path of the heart that, despite suffering or disability, brings true joy and allows us to LIVE.

"For me, the heart is never disabled because it has so much to offer, we have so much to learn within each of our limits and let us not forget that we must find perfection in imperfection so that everyone has their place. »

Thank you, Louise! Our collective priority should be "aid in living." This term was frequently used during the public hearings of the Parliamentary Committee studying Bill 11.

Can "aid in living" coexist with "aid in dying," when offered for people with a severe and incurable neuromotor disability? It is important to remember that, even during difficult times, we are convinced that aid in living- without an exit door to death - must guide us as a society. Such is the philosophy of all our suicide prevention campaigns.

Quebec must not make the mistake of harmonizing with Bill C-7 and must refuse to include disability in its law on end-of-life care. The federal safeguard of a minimum waiting time of 90 days between the first evaluation and the day medical aid in dying is performed for people who are not at the endoflife (meeting the other criteria of federal law) is a delusion. Adaptation to a disability can take many years and it is the quality of care, access to services and the benevolent presence of loved ones that must be put forward collectively.

Recommendation 2: Rather than crossing the frontier of disability to obtain medical assistance in dying, a massive investment in everything that promotes aid in living should be promoted.

⁶Non-exhaustive list of distinctions awarded to Ms. Brissette.
https://fr.wikipedia.org/wiki/Louise_Brissette

4- The frontier of institutional constraint imposed on palliative care homes

(The bill provides) that palliative care hospices may not exclude medical aid in dying from the care they offer.

Excerpt from the Explanatory Notes to Bill 11

We are disappointed with the reinstatement of this measure in a more restrictive framework than the one suggested in the previous Bill 38, which included the crucial phrase "with some exceptions."

Before long, Quebec will have only five palliative care homes that do not provide medical aid in dying (plus a private hospital and a children's palliative care home that does not provide MAiD despite the clientele including a few young adults).

Legally requiring these homes to provide medical aid in dying is in our opinion an arbitrary and cruel measure.

The *Alliance des maisons de soins palliatifs du Québec* brilliantly presented its call to withdraw section 9 from the bill during its [public hearing](#) and in [its brief](#). We will not repeat their complete argument here, but their response to one of the main myths used to justify imposing MAiD on these homes merits special attention:

Finally, it is incorrect to believe that a palliative care home that does not provide medical aid in dying within its walls abandons a person in an ambulance in a state of pain and distress in order to avoid them spending their final moments in the home.

Palliative care homes excel at meeting the expectations of potential residents by clearly announcing their services. They offer palliative care at the end of life. The few people who choose to resort to MAiD do so in spite of the high quality of care they receive.

We must remember that medical aid in dying is not part of the palliative care philosophy. It is no surprise that all the movement's founders opposed and continue to oppose euthanasia/medical aid in dying. This concept contradicts the palliative culture, which does not aim to prolong or shorten a patient's life.

We believe it is healthy that a few locations (7 at the moment) choose not to provide medical aid in dying, in order to meet the expectations of the community, health professionals, volunteers, and, needless to say, patients. There are no surveys on this topic, but we do receive testimonials from people nearing the end of their lives who prefer to spend their final months, weeks, or days in a "safe" environment where medical aid in dying is not available. Of course there is no doubt that all homes are safe environments. But we are aware that, despite the information provided to

reassure them, some individuals still want to end their lives in a location where medical aid in dying is not available. We believe we must also respect their decision by maintaining a few homes in Quebec that only provide palliative care.

Impacts of such legislation on the development of new palliative care homes

There will undoubtedly be groups and individuals interested in building additional palliative care homes to meet the population's enormous needs in the coming years. These citizen efforts are critical to our collective well-being. We are convinced that if this legislation is adopted, some will not see the light of day. Some potential promoters will reluctantly abandon their projects if compelled to provide induced death, which is contrary to the basic spirit of palliative care.

Thus, in addition to suppressing the institutional freedom of living environments that choose not to provide MAiD, section 9 of the bill will stymie the development of new palliative care home initiatives.

Recommendation 3: Rather than crossing the frontier of institutional constraints placed on palliative care homes, we should respect the preferences of the few living environments that do not provide medical aid in dying.

5- The frontier of mental disorders

The bill provides that a mental disorder is not considered to be an illness.

Excerpt from the Explanatory Notes to Bill 11

We applaud the legislator for not giving into pressure to include mental illness as a criterion for granting medical aid in dying. We must avoid falling into the trap of harmonization with federal legislation, as we did with the issue of disability. The Select Committee on the Evolution of the Act Respecting End-of-Life Care's decision not to contemplate this extension appears prudent.

We frequently hear in the public sphere that there is no consensus on the issue **yet**, implying that it is only a matter of time. However, the reality of mental disorders is unchangeable: they are never irremediable. Some people will have to live with these disorders for the remainder of their lives, while others will not. Experts frequently tell us that we cannot predict their path.

In this regard, we strongly recommend the work of The Expert Advisory Group (EAG) on Medical Assistance in Dying, available on their website www.eagmaid.org.

While we cannot foresee the course of their mental illness, much can be done to assist our fellow citizens suffering from it. The top priority continues to be addressing unacceptably long waiting lists for psychiatrists, psychologists, and sufficient social support.

We will work diligently with organizations nationwide to ensure that this threat does not materialize, as Canada prepares to give medical aid in dying to people whose only medical condition is a mental disorder (March 17, 2024). Even if it becomes a reality, we hope that Quebec will not pass it into law on behalf of all the Julie Senécal's⁷ in Quebec.

Recommendation 4: Rather than potentially crossing the line of mental illness to access medical aid in dying, it would be preferable to send a clear message to the federal government: Quebec does not want this access.

⁷ To view Julie Senécal's testimony, a citizen with mental health challenges with whom we testified during the public hearings of the Select Committee on the evolution of the Act respecting end-of-life care. <https://vivredignite.org/participation-vdd-commissionqc-2021>

Conclusion

Medical aid in dying in Quebec The coming frontiers

The coming frontiers of MAiD access are already within sight: mature minors and fatigue of living in the elderly, a topic that the *Collège des médecins du Québec* has already invited us to discuss.⁸

The jurist and ethicist Pierre Deschamps, member of the Committee on end-of-life care, concluded a conference on October 24 before a French audience on these words: *It is not impossible that older persons and those whose lives have been "fulfilled" will one day be able to receive medical aid in dying. [...] In the long run, and this is my opinion, we can envision in Canada, with regard to the Charter of Rights and Freedoms, the recognition of every person's basic right to choose the moment of his death regardless of his condition.*⁹

Ms. Sonia Bélanger, the Minister in charge of Bill 11, expressed her desire that MAiD remain a last resort. Unfortunately, that is not factually the case. Every week, patients are offered MAiD without having considered it. Health professionals often feel powerless to assist their patients given the lack of resources. As illustrated by a March 26¹⁰, Radio-Canada report, they may propose MAiD as a solution to a lack of resources.

When effective palliative care is not accessible everywhere, no true choice between palliative care and medical assistance in dying exists. The MAiD offer was never intended to fulfil economic imperatives, but it does have economic consequences. This leads us to emphasize the importance of prioritizing investments in "aid in living," especially palliative care at home. The rapid expansion of MAiD administration (7% of all deaths in Quebec) must challenge us. We must consider the reasons provided for choosing MAiD, particularly the fear of becoming a burden to one's loved ones and to society.

Our most defenceless loved ones should never have that concern. As a society, we must provide aid in living to all our citizens nearing the end of their lives. And as a family member, a friend, or a co-worker, we must accompany our loved ones with a message of encouragement: we will never abandon them by offering MAiD. They must understand that losing autonomy through old age, sickness, or disability will never jeopardize their dignity.

⁸<http://www.cmq.org/page/fr/college-favorable-elargissement-troubles-neurocognitifs-propose-balises-sante-mentale.aspx>

⁹At the bottom of the page listing the conference *Autour de la Loi sur l'aide médicale à mourir (AMM) québécoise: aspects éthiques, juridiques et sociaux* <https://vivredignite.org/amm-au-quebec-france>

¹⁰<https://ici.radio-canada.ca/nouvelle/1966196/soins-palliatifs-domicile-quebec>

Bill 11

The four recommendations of the Living with Dignity citizen network to the Committee on Citizen Relations

Recommendation 1: Rather than crossing the line of incapacity to access medical aid in dying, it would be preferable to invest extensively in geriatric care and support for people living with a neurocognitive disorder. By implementing best practices to treat the symptoms of illnesses and accompany the loss of capacity, they no longer need to fear being deprived of their dignity.

Recommendation 2: Rather than crossing the frontier of disability to obtain medical assistance in dying, a massive investment in everything that promotes aid in living should be promoted.

Recommendation 3: Rather than crossing the frontier of institutional constraints placed on palliative care homes, we should respect the preferences of the few living environments that do not provide medical aid in dying.

Recommendation 4: Rather than potentially crossing the line of mental illness to access medical aid in dying, it would be preferable to send a clear message to the federal government: Quebec does not want this access.



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