



LIVING WITH DIGNITY

Briefing by the *Living with Dignity* citizen network

Select Committee on the Evolution of the Act
respecting end-of-life care

*The solution to ensure “dying with dignity” is to be found in a
competent, palliative approach, with respect,
accompaniment and tenderness.*

Excerpt from an open letter of Dr. André Bourque, September 2009
Co-founder of Living with Dignity (1947-2012)

August 6th, 2021

Introduction

“To promote the protection of life, the inherent dignity and the accompaniment of people made vulnerable by illness, old age or disability”, such is the mission of our citizen network based in Quebec, founded in 2010 at the dawn of the debate surrounding the Select Committee on Dying with Dignity.

Since then, close to 5,000 people have [deemed it important to sign our Manifesto](#) (90% of them being from Quebec).

This is our third brief presented to the Quebec National Assembly over the years. The first two were tabled:

- August 18, 2010 to the Select Committee on Dying with Dignity;
- September 25, 2013 to the Committee on Health and Social Services (Bill 52).

Reading these documents ([available on our website](#)) reminds us of how far we have come in the past 11 years.

Although medical aid in dying (MAiD) is well established in Quebec and Canada, a large segment of the population refuses to recognize euthanasia/medical aid in dying as a form of care and are concerned about the provisions of this law. We strive to represent the legitimate fears of these people in the public arena at a time when the space to do so is increasingly unavailable.

We are grateful for the opportunity to participate in this parliamentary exercise and remain convinced of the importance of widely sharing the reasons that motivate our commitment as citizens. Some might call us candid or naive, but we believe the Committee members when they say that their decisions are not made in advance. Depending on their judgment, the doors to a possible extension of accessibility to MAiD may remain closed.

In a democracy, the government has a grave responsibility to protect all its citizens - the minority who demand changes in the law, as well as the majority who risk being harmed by such changes. And in this case, the stakes are significant: death

itself. The more the access to MAiD is expanded, the more the public good is threatened.

We hope that this brief will deepen the reflection initiated during phase 1 of the Select Committee. We would like to commend the work done by the Committee's team in preparing the consultation document.

We strongly recommend that you read the Consultation document prior to reading our brief, as it lays the foundation for the current debate. In the pages that follow, our brief will address the following points in order:

- 1- The challenges of continuing to mobilize against expanded MAiD access;
- 2- Advance requests and MAiD for persons who have become incapacitated;
- 3- MAiD for mental disorders;
- 4- Mandatory referral for MAiD;
5. Preservation of funding for hospices that refuse to offer the MAiD;
- 6- Issues related to the eventual extension of MAiD to mature minors;
- 7- In conclusion, rediscovering the treasure of palliative care.

In the appendix, you will find all of our recommendations.

Thank you for your attention to our reflection as citizens,

Alex King
President
Living with Dignity Citizen Network

1- The challenges of continuing to mobilize against the expansion of MAiD accessibility

Since the implementation of the Quebec law concerning end-of-life care in 2015 and the 2016 amendments to the Federal *Criminal Code* (C-14), medical aid in dying is legally available in Quebec and Canada to certain groups of citizens. Organizations working to expand what they call the “right to die with dignity” have had a field day since then, receiving a great deal of media attention and government funding. *Dying with Dignity Canada*, [even received charitable status in 2018](#). Our attempt to achieve the same recognition (2020) was unsuccessful. Much to our disappointment, we were turned down by the *Canada Revenue Agency*, even though the group at the opposite pole of our mission shares many similarities with us in its core areas of action.

The questioning of further expansion of accessibility to MAiD also seems to be much better received if it does not come from groups and individuals who oppose them in *all* circumstances. In the political and media arena, the question keeps coming up: “But are you also against medical aid in dying at the end of life?” An affirmative answer to this question seems to discredit the rest of a rational argument shared even by the majority of the international medical community.

The various groups and individuals advocating for greater access to MAiD have for years caricatured opposition to euthanasia as if it could only be the result of religious propaganda.

However, the concerns come from a wide range of personalities whose reasoned and profound argumentation is inspired by a wealth of scientific literature and philosophical points of view that transcend spiritual, humanist or political movements. From the very beginning, we have chosen to be a non-religious and non-political organization in order to welcome people from all horizons under the same umbrella.

Living with Dignity collaborates with a broad, diverse coalition of groups and individuals who may or may not support MAiD in certain circumstances. They know of our strong opposition to MAiD and we work together in mutual respect.

While we can never trivialize the negative impact of MAiD in Quebec, we are committed to a caring and peaceful dialogue in our public and private interactions with various civil society actors, regardless of their views on the subject.

And while we strongly disagree with those who hope to push the limits of access to MAiD ever further, we are aware that their actions stem from a desire to do the right thing. The philosophical divide between us remains (as it was at the very beginning of the debates in 2010), based on two different views of human dignity and the new opportunities that life affords us when we are well cared for.

For the citizen network **Living With Dignity** and still, for a significant part of the Quebec population, this dignity is something which can never be lost since it is inherent to our nature as human beings.

2 – Advance requests and MAiD for persons who have become incapacitated

Despite significant pressure during the debate on Bill C-7, the Canadian Parliament wisely refused the amendment proposed by the Senate that would have opened the door to advance requests allowing MAiD for persons who have become incapacitated.

Quebec therefore has a degree of flexibility to refuse this new opening as well. In the name of autonomy and a reductionist vision of dignity, many groups took advantage of the first phase of the public hearings to request this access with a series of guidelines that differ according to opinion.

Testimonies in favour of this opening have obtained a large media presence in the last few years. They put forward very different conceptions of dignity. The desire to die before reaching various stages of illness (neurocognitive or otherwise) is rooted in an increasingly widespread philosophy that the dignity of each being hangs by a thread, when in fact it is inherent and inalienable.

As an example, wearing a “diaper” seems to be a critical challenge. For some, it would be better to die than to live in this condition. Repeated *ad nauseam*, this idea is making its way into the collective unconscious. We are saddened that our decision-makers do not speak out to remind us that although this stage is difficult to contemplate for many, it never takes away one's dignity and it does not abolish the bonds of love with those who are dear to us. By opting for silence, what message are we sending to the thousands of Quebecers living in this situation? That wearing incontinence underwear (or being unable to read, wash oneself, etc.) would be an acceptable criterion for asking a third party to take one's life?

Many people want advance directives because they have seen relatives or friends going through difficult stages related to diseases such as Alzheimer's. Given the disparity in treatment in long-term care facilities, we understand their fear concerning the progression of the disease.

But as some experts have reminded us before ([Dr. Félix Pageau's briefing](#) makes a brilliant case for this, as well as his book *“La responsabilité de protéger les personnes âgées atteintes de démence.”* Manifeste, P.U.L. 2020), that we must instead “value real human dignity despite ageism, mental health stigma, physical and cognitive disabilities.” We also support the words of Dr. Harvey Max Chochinov, a Canadian physician who leads the research team that developed the Dignity Model and Dignity Therapy: “Active euthanasia in dementia (MAiD) is not a treatment or a care. It is an admission of failure of contemporary medicine. The feeling of loss of subjective dignity is obviously valid, but it can be treated” (Chochinov, 2012).

Our recommendations:

We should not, in any way, consider access to MAiD by advance directive for persons who have become incapacitated. These individuals have always been the subject of special concern for protection by the state and society. Whether justified or not, the fear of loss of dignity should never place a health care professional in a situation in which he or she will have to take the life of a person who is unaware of the impact of the action about to be taken.

The government must combat the sense of loss of social dignity through awareness campaigns aimed at populations who are most vulnerable to ableism and ageism. We are not yet fully cognizant of the impact of the repeated media coverage of the idea that loss of certain faculties would inexorably lead to a loss of dignity. There is a very real danger that some of our fellow citizens will fear becoming a burden to their loved ones and to Quebec society. These measures are crucial to reassuring them.

3- MAiD for mental disorders

With the adoption of the Federal *Bill C-7*, the door to MAiD will open in March 2023 for people who claim mental illness as their only medical condition. As we pointed out during the debates last Spring, we consider this scheduled opening highly irresponsible when the supply of mental health care is deficient throughout the country. Unfortunately, Quebec is no exception to this reality, as Ms. Julie Senécal can attest. We take advantage of this brief to share her experience with you:

“Let me introduce myself: Julie Senécal, 48 years old, mother of 4 daughters, epidemiologist by training. Place of residence: the Outaouais. In 2013, I sank into a major depression that lasted 8 years, and I am still fragile, despite therapies and (poorly) available resources. During these 8 years, I was hospitalized 5 times for suicide attempts. It wasn't until my fourth hospitalization, in 2021, that the medical staff referred me to resources in the community to properly support me upon discharge. It took more than 6 years of psychiatric consultations to receive a diagnosis of borderline personality disorder. During this time, in order to "forget" my depression and my lack of desire to live, I faced challenges with alcohol.

People suffering from mental health challenges who have suicidal thoughts or who make suicide attempts, would be predisposed to ask for MAiD during periods of distress, depression, anxiety. They are often influenced by their mental health status, stigma, lack of resources (psychologists, psychiatrists, social workers, cognitive behavioural therapies, mindfulness, etc.), and sometimes also under the influence of drugs, alcohol or gambling.

That said, MAiD for people with mental health challenges is a very complex issue and an ethical challenge. There is also the challenge of the lack of appropriate resources. Mental health challenges, if not managed promptly by specialists AND long-term therapies, can often lead to major depression, generalized anxiety and even suicide.

*When a person with mental health challenges has suicidal thoughts or attempts suicide, they need **immediate** help and resources. At this time, only*

telephone lines such as Tel-Aide that are available. Once the person hangs up the phone, he or she is left alone in their despair, unless they have been advised to go to the Emergency Room at the hospital. If this is the case, ideally they should be taken care of with resources as soon as they arrive at the hospital. Currently, people who come to the hospital following a suicide attempt are often left alone in a room, and are only occasionally under supervision. In the hospital, there are no resources such as psychologists or social workers who come to see patients promptly. Often it can take up to a week or more of hospitalization before the patient can finally see a psychiatrist. In rare cases, some nurses will take a few minutes to ask the patient how he/she is doing, but no more. They are not trained to offer psychological support to the hospitalized person. The meeting with the psychiatrist is limited to the prescription of medication. In most cases, when the patient is discharged from the hospital, he/she returns home under the same conditions and is placed on waiting lists to access services (psychiatrist, psychologist, therapists, social worker, etc.). In my case, I had to be hospitalized five times for five suicide attempts between June 2013 and May 2021 and it wasn't until the spring of 2021 that I was assigned resources and presented with a discharge plan and a 'safety net', before leaving the hospital.

During my major depression that started in June 2013, I sought help to see a psychologist and psychiatrist. I was on the waiting list for 8 years (in the Outaouais region) before I could get access to a psychiatrist in the public sector and the same number of years before I could get access to a psychologist in the public sector. I was fortunate to have good insurance, because while waiting all those years for help, I was able to access services in the private sector in Ontario (I live in Quebec, in the Outaouais region, where private resources are difficult to access). Even in the private sector, I had to wait 2 years before I could access help. This long wait contributed to two suicide attempts. During this period of intense distress, with no resources available, if medical aid in dying had been offered to me, I would have signed "yes", seeing no other way out. Today, I finally have the chance to be well

taken care of medically (by a psychiatrist and family doctor), socially (by social workers, psychologists and support groups) and I can enjoy life and my 4 children with happiness. I have regained my 'joie de vivre'. However, I needed help and guidance spanning several years to get here."

The feedback we receive from the field confirms that this testimony is not anecdotal. On the contrary, it seems absurd to us to even consider a new access to MAiD in this context.

It must be understood that life expectancy for people with mental disorders will be reduced by several years due to MAiD. Not to mention the therapeutic developments still to come that will not benefit such patients - a flagrant injustice.

The experts you have consulted suggest that access to MAiD should be limited to extreme cases where, after years of therapy, all treatment options have failed. The unpredictability of the trajectory of various disorders leads us to advocate great caution even in these cases.

Our recommendations:

We are fundamentally opposed to MAiD for mental health conditions. If, as planned, MAiD becomes available under Federal legislation in March 2023, we hope that Quebec will adopt the strictest possible guidelines. In the case of cannabis, Quebec has chosen to err on the side of caution by allowing its use only by people 21 years of age and older. We encourage it to adopt the same attitude in the area of medical aid in dying for people whose mental health is faltering, by taking a leading role in implementing the strictest guidelines in the country for access to MAiD. We hope other provinces will follow suit.

There is an urgent need for massive investment in mental health care. We agree with many that the effects of the pandemic will increase the demand for care, while the supply of care remains far below the expressed needs of the population. At a time when people with mental illness may be contemplating suicide, we also believe it is urgent to improve access to quality palliative care for them as well.

4- Mandatory referrals for MAiD

Last May, together with the Physicians Alliance against Euthanasia, we prepared a submission to the Committee revising the International Code of Medical Ethics of the World Medical Association. We felt it was important to participate in this broad public consultation because the Committee is considering “the addition of a requirement for prompt and effective referral to another qualified physician in situations where a physician objects for reasons of conscience to a procedure requested by a patient.” Our full response, from the perspective of medical aid in dying, is available online:

<https://vivredignite.org/en/2021/06/submission-2021-intl-code-medical-ethics>.

Here is an excerpt:

“An effective guidance requirement in the International Code of Medical Ethics would be in direct contradiction to the well-established policy of the World Medical Association.”

“The vast majority of patients facing serious illness want to continue to live and there is a need for physicians who will accompany them without wavering, while guiding them through the necessary care choices they must make as they approach natural death. Many Canadians are concerned that physicians will steer them towards a choice for MAiD which is contrary to their wishes, and they seek reassurance that their primary care physician will never do so. However, there are already many examples of physicians unable to fulfill this mission because of coercive regulations that require them to initiate the MAiD application process for every patient who expresses a wish to die, or to refer them to a colleague who will.”

Just as the Quebec law respects the conscience of health professionals by not forcing them to administer MAiD, we believe it is essential that they should also never be pressured to make direct referrals.

Our recommendation:

Ensure that a physician can always withdraw from a case involving 'medical aid in dying' without actively facilitating what he or she considers to be euthanasia by:

- informing the Management of their institution
- providing a general information number, such as Info-santé, for an outpatient.

5- Preservation of funding for hospices that refuse to offer MAiD

Quebec's End-of-Life Care Act demonstrates wisdom in allowing hospices the freedom to choose whether or not to administer medical aid in dying.

To date, 19 of the 37 hospices in Quebec offer MAiD. The pressure is on those who still resist the introduction of medical aid in dying in a palliative context. We are convinced of the relevance and necessity of maintaining places where euthanasia will never be performed. Even if external resources administer MAiD, this presence contradicts the palliative philosophy developed since the 1970s by Quebec pioneers like Dr. Balfour Mount. Like him, we reiterate the incompatibility between the goals of palliative care and those of assisted dying.

Despite the guidelines surrounding access to MAiD, we hear the voices of patients who prefer to live out their end of life in places where it is not offered. Since all public health institutions are obliged to offer MAiD, the least we can offer these individuals are hospices that are free of this practice. It is important to remember that hospices were designed to be places where people choose to live out their final days, not to die induced deaths.

Our recommendation:

That Quebec hospices be allowed to continue to care for people at the end of their lives, without financial or other pressures to offer medical aid in dying.

6- Issues in the eventual accessibility to MAiD for mature minors

Those who spoke of a probable slippery slope following the introduction of MAiD in Quebec and Canada do not seem to have been wrong. Year after year, the access that was initially announced for exceptional cases is becoming more liberal. As the next debate is about “mature minors”, we would like to briefly address it.

In 2018, the Council of Canadian Academies received a mandate from the Ministers of Health and Justice to study the issue of MAiD for mature minors. After reviewing the report produced, we applaud the Canadian government's decision not to add this potential expansion during the debates surrounding Bill C-7. Similarly, we thank the Select Committee on the Evolution of the End-of-Life Care Act for not considering it.

We hope that Quebec will also choose the path of prudence on this issue by ignoring calls to open this thorny debate.

Our two main objections to considering requests for MAiD from “mature minors” are:

- 1) The concept of “mature minors” is not a medical concept and is the subject of much criticism in the scientific literature. The most recent neuroscience findings regarding brain development tell us that a young person's judgment becomes mature long after the age of majority.
- 2) Although there are a few young people who have applied for MAiD in the two jurisdictions that allow it (the Netherlands and Belgium), the premature death of even one immature young person in view of his or her incomplete neurological development must be considered a tragedy.

Our recommendation:

Ignore calls to consider MAiD access to “mature minors” and devote more effort to developing and providing supportive resources for them.

Conclusion: Rediscovering the treasure of palliative care

Palliative care that is more accessible to those who need it and are not at the end of life remains for us one of the most promising ways to respond to the fears of suffering or loss of dignity that have been raised in order to extend MAiD by advance directives to persons who have become incapacitated or for cases of mental disorder.

Let's remember that when the End-of-Life Care Act was passed, the Minister of Health at the time assured us that the purpose of the Act was to ensure a significant development of palliative care services in our health care system. Yet, very little work has been done in this area since 2015.

In recent years, there has even been some rhetoric that seems to imply that the inaccessibility of palliative care has no impact on the demand for MAiD. This is evidenced by the fact that many people have chosen to receive medical aid in dying after receiving palliative care. There is no doubt that patients may be more open to MAiD when health professionals present it as complementary end-of-life care to palliative care. The studies cited that suggest that people who seek MAiD have already had palliative care also seem methodologically weak. They do not define whether or not patients have received comprehensive and expert palliative care service.

When palliative care giving environments remain free from medical aid in dying, requests are extremely rare, if not non-existent. The vast majority of physicians working in dedicated palliative care settings still refuse to administer MAiD.

To contribute to the reflection on end-of-life care, we are launching a new series of videos to illustrate our philosophy:

The treasure of palliative care



10 minutes long and available in English and French, the **Treasure of Palliative Care** answers six key questions to help you learn more about palliative care before you make end-of-life choices:

- Is palliative care only for people dying of cancer?
- Where can we receive palliative care?
- Does palliative care hasten death?
- Does morphine cause death?
- Should pain be part of the end of life?
- Is medical assistance in dying part of palliative care?

In addition to the brief answers provided in the video by Dr. Golda Tradounsky and Dr. Patrick Vinay, there are longer versions available for those who wish to go into more detail on any of the topics discussed.

All these videos (14 in total) can be viewed at the following address:

vivredignite.org/treasure



**Recommendations of the
Living with Dignity citizen network
to the Select Committee on the Evolution of the Act
respecting end-of-life care**

1) We should not, in any way, consider access to MAiD by advance directive for persons who have become incapacitated. These individuals have always been the subject of special concern for protection by the state and society. Whether justified or not, the fear of loss of dignity should never place a health care professional in a situation in which he or she will have to take the life of a person who is unaware of the impact of the action about to be taken.

2) The government must combat the sense of loss of social dignity through awareness campaigns aimed at populations who are most vulnerable to ableism and ageism. We are not yet fully cognizant of the impact of the repeated media coverage of the idea that loss of certain faculties would inexorably lead to a loss of dignity. There is a very real danger that some of our fellow citizens will fear becoming a burden to their loved ones and to Quebec society. These measures are crucial to reassuring them.

3) We are fundamentally opposed to MAiD for mental health conditions. If, as planned, MAiD becomes available under Federal legislation in March 2023, we hope that Quebec will adopt the strictest possible guidelines. In the case of cannabis, Quebec has chosen to err on the side of caution by allowing its use only by people 21 years of age and older. We encourage it to adopt the same attitude in the area of medical aid in dying for people whose mental health is faltering, by taking a leading role in implementing the strictest guidelines in the country for access to MAiD. We hope other provinces will follow suit.

4) There is an urgent need for massive investment in mental health care. We agree with many that the effects of the pandemic will increase the demand for care, while the supply of care remains far below the expressed needs of the population. At a time when people with mental illness may be contemplating suicide, we also believe it is urgent to improve access to quality palliative care for them as well.

5) Ensure that a physician can always withdraw from a case involving ‘medical aid in dying’ without actively facilitating what he or she considers to be euthanasia by:

- informing the Management of their institution
- providing a general information number, such as Info-santé, for an outpatient.

6) That Quebec hospices be allowed to continue to care for people at the end of their lives, without financial or other pressures to offer medical aid in dying.

7) Ignore calls to consider MAiD access to “mature minors” and devote more effort to developing and providing supportive resources for them.

Note that we strongly support the 14th recommendation of the Expert Panel on Incapacity and Medical Assistance in Dying:

That the efforts currently being made by the government in the area of palliative care be stepped up and that the necessary measures be taken to ensure that quality palliative care in sufficient quantity is offered throughout Quebec, both in institutions and at home, to people who need it, including those who are incapacitated and their caregivers.