

AVIS SUR LE PROJET LOI 38

Bill 38, an Act to amend the Act respecting end of life care and other legislative provisions introduces significant modifications that will impact generations to come.

Precedents that fundamentally will change the direction of a society with major implications for our institutions and for how we as a society care for the vulnerable in their suffering.

When we define death with dignity we simultaneously define life not worthy of living. When we define death with dignity we impact not only end of life care but our concept of care. Although these are individual choices they remain values which are tightly interstitched and woven together with cultural and societal mores and other persuasive considerations.

As we speak, grandchildren are witnessing and learning new barometers of tolerances and definitions of acceptable or non acceptable disabilities.

Children as young as 11 are being told Grandma is courageous right before they say their goodbyes and MAID is administered! This Bill must be rigorously scrutinized.

Permit me to first commend the Select Committee on The Evolution of the Act Respecting End-of-Life Care for all their work culminating in their report from which Bill 38 takes its guidance. I particularly applaud both Recommendation 11 as well as the recommendation for the inclusion of Advance Requests (although with a few modifications) .

I think their tireless work makes it all the more imperative that we do not rush to adopt Bill 38, an Act to amend the Act respecting end of life care and other legislative provisions. Rushing such a crucial and complex bill just because it is an election year is pure and serious folly.

Notwithstanding, I appreciate that there are people waiting for an end to their suffering, but there may also be persons who for the wrong reasons by the wrong methods may lose their lives.

Those deaths are already on the increase just in the past year and thanks to the press reporting on same (attached in appendix, titles below) we can glean some insight into the **causes** for these MAID failures.

Unfortunately, our statistical compilation and analysis, annual and five year reviews, both federally and provincially do not even collect this data. Neither do they collect certain types of complaints, nor concerns issued by family members to the competent professional , nor do they collect feedback from families impacted and oftentimes torn apart forever, as a result of MAID. All this important information is necessary for any rigorous performance review, measurements needed for any critical analysis that can lead us to adapt and modify effectively, our relevant laws and the organizational structures charged with regulating their application.

These articles demonstrate this as well as some aspect from each of the debates I call attention to in this paper. They also relate the sad outcomes we all want to avoid and must. This law ends lives, there is no going back so we have to get it right.

- **Police Investigating Medically Assisted Death Of B.C. Woman.**
Avis Favaro CTV National News Medical Correspondent
- **Woman with disabilities approved for medically assisted death relocated thanks to 'inspiring' support**
Avis Favaro CTV National News Medical Correspondent
- **Woman with chemical sensitivities chose medically-assisted death after failed bid to get better housing**
Avis Favaro CTV National News Medical Correspondent
- **A rare look at Canada's growing demand for medical assistance in dying (extract)**
Avis Favaro CTV National News Medical Correspondent
- **Opinion: Advance directives for assisted death a recipe for abuse**
Catherine Ferrier for Montreal Gazette
- **Extract from Select Committee**
- **My sister's case (in main text)**

■ Therein lies your **FIRST DEBATE FOR THIS BILL: EXPANDING THE COLLECTION OF MEANINGFUL DATA.**

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You do not even have any effective oversight mechanisms to ensure that all essential data reaches you from the MAID process and competent professional. More importantly you have no oversight mechanism in place to ensure that your 2nd physician **overseer** himself receives all the relevant information from the first physician in a punctual and timely manner, which could affect more than data collection but could result in failure to assess all criteria correctly and administer assistance in dying in error.

If for example a family member or concerned person signals something of concern to the physician-assessor, there is no obligation for him to respond to these concerns although he is obliged by law to address the matter with the patient. There is no way that the concerned person can be assured that he has, nor that he puts it in his report for the 2nd physician to review and ultimately the government to see. **Having the second physician confirm in writing punctually to the person who signaled the concern, that their concern has been considered and addressed** would provide oversight, possible protection of the patient, transparency and accountability. However all of this is predicated upon the first physician addressing the concern and including it in the file.

To ensure that this is done is **ultimately why I see the necessity of separate entity, a limited mediation board to deal exclusively with MAID for Quebec, composed of Doctors, to deal with concerns relevant to the application of the MAID law.** Thus when concerns are expressed to the first physician and simultaneously to this board, the board's limited mandate is to ensure by signed confirmation from both doctors that they have indeed received and addressed the concern. Then a copy should be forwarded to the party who signalled the concern, in a time-sensitive fashion, indicating that the matter has been addressed by both doctors. Without this there is absolutely no oversight, no transparency and accountability and ultimately no protection. It is the best we can do with medical files being private in order to signal possible abuses that could exist and that could compromise the assessment's faithfulness to criteria and adherence to the law designed to protect the vulnerable, whatsoever the source of those abuses. Ideally a justification to the mediation board would enhance the rigorousness but failing the likelihood of that, the signed confirmation of both physicians is the minimum protection

concerned family members and others must insist upon. If concerns are still not satisfied then the College des Medecins will have to be implicated.

This becomes important because it is **breaking more families apart** as it did mine. I had been completely involved, albeit confined in another province due to COVID, but on FaceTime multiple times daily **until**, I expressed reservations to the family caregiver and my sister who was requesting MAID that there are criteria to meet, one being an advanced state, it was too soon. Having just had a early Alzheimer's diagnosis, both parties felt my concern was obstructionist and I was kept in the dark thereafter.

My sister had been diagnosed with early Alzheimer's disease initially as most other people are, with a battery of questions to assess cognitive function and memory. However she was fortunate to participate in a Clinical trial in a University hospital in Toronto which would only admit **early** Alzheimer's' subjects. Brain imaging technologies to test for evidence of tau tangles and amyloid plaques as well as a series of other tests were performed. They concluded she had **early stage Alzheimer's**. However once she received confirmation of the diagnosis, she withdrew from the study and opted for MAID.

90 days after these tests were completed, my sister and family caregiver went ahead with the MAID request. There was no evidence that there were rapidly progressing symptoms. I was there by then (august, September and October stays). This had been brought to the Doctor's attention by another family member but we never got any feedback, never will, and certain family ties are irreparably damaged and we are hearing about this more and more often, serious collateral damage of the way the MAID process is designed.

■ Therein lies your **SECOND DEBATE: DEVELOP ACCOUNTABILITY ,
TRANSPARENCY AND TIMELY -PUNCTUAL OVERSIGHT
MECHANISMS.**

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■ The **THIRD DEBATE: REFINING FUNDAMENTAL CORE CRITERIA,
BOTH NEW AMENDMENTS AND EXISTANT IN THE MAID
PROCESS.**

THE LANGUAGE OF CRITERIA, NEW AND EXISTANT

I appreciate the manifold difficulties involved in establishing the criteria for MAID at all stages of the process including eligibility, management and application. Nevertheless too much **ambiguity in the language** I fear, is exploitable:

- it does not **ensure** rigorous and exhaustive interventions;
- it easily lends itself to **misinterpretation** in the hands of less competent and ardent professionals which risks violating the spirit of the law as intended by opening up far too broad a usage which is in evidence now and which unfailingly will continue to swell and expand into the future.

The Commission recognized the confusion promoted in the language of some of the criteria and succeeds in Bill 38 Amendment 29.2, (1),(2) and (3) to address it as well as other issues this Amendment solves but addendum 26 (3) surely risks opening the portals wide again and far wider.

THE CONSEQUENTIAL NEW AMENDMENTS

Amendment 26 (3) under the Special provisions applicable to contemporaneous requests for medical aid in dying.

It changes the criteria (3) to include "a serious and incurable **neuromotor disability.**"

First off, I do not believe seeing this anywhere discussed in the Report from the Select Committee, nor did it appear anywhere in the recommendations although maybe that does not matter.

Although this criteria approaches and is more in line with the Federal MAID Law criteria, I take issue with both jurisdiction's texts in so far as it is at **cross-purposes to Criteria (4)**.

A neuromotor disability **can** be both an acquired condition and one that is **static**, that is to say, not progressive. So first off in Criteria (4) both terms, "advanced" and "decline" refer to comparative states diminish **over** the passage of time. If it is a static disability it will not be getting worse, it stays the same. In my opinion to accept the amendment (3) would necessitate changes to the language of criteria (4).

More significantly however, with the inclusion of a neuromotor disability criteria, persuasive arguments can and will be made that other predominantly bedridden conditions and disabilities should equally have this same right and consideration as they may share the same "quality of life" issues: the frail elderly person, most of the seniors in our CHSLDs, and others. How far do you open it? The ever widening portal is in such stark contrast to conditions permitted for medical directives the spirit of the law seems to be floundering **now** in the surge of requests. We must reflect upon the contrast, as I believe it signals there is a major problem here and the floodgates are opening up to much, too fast and recklessly and not uniformly applied across the province.

Medical Directives involve these 5 procedures that they can be directed not to perform

- (1) Cardiopulmonary resuscitation,
- (2) ventilator assisted respiration,
- (3) dialysis,
- (4) force-feeding and hydration
- (5) artificial feeding and hydration

For only the following situations

Situation of severe, irreversible loss of cognitive functions:When a person is in a comatose state that is judged irreversible, that is, that they are permanently unconscious and confined to a bed, without any possibility of regaining consciousness.

When a person is in a permanent vegetative state, that is, they are unconscious, but some reflexes are maintained, such as the capacity to open and close the eyes, or reaction to pain.

Another situation of severe, irreversible loss of cognitive functions:

When a person is suffering from severe, irreversible cognitive impairment, without any possibility of improvement, for example Alzheimer's disease or another type of dementia at an **advanced** stage.

Amendment 29.2 (1) (2) (3) under the Special provisions applicable to advance requests for medical aid in dying.

I **applaud** this amendment particularly as it relates to Psychological suffering and theoretically it is consistent with Recommendation 11 of the Report however

I ALSO BELIEVE THIS AMENDMENT MUST EXTEND TO CONTEMPORANEOUS REQUESTS AND ASSESSMENTS

It can reign in one of the major flaws in the existant criteria eligibility where "psychological suffering" is incorrectly being used leading to premature deaths, contributing to avoidable deaths and I do not believe it complies with the spirit of the law.

The professional must ensure that the suffering described in the request meets the following criteria:

- (1) be **medically recognized** as being suffering that can result from the illness from which the patient suffers

This should be **Applied to a contemporaneous request as well, however I wish to highlight the benefit with regard to evaluating psychological suffering.** This confers upon the competent professionals, the responsibility of assuring that the psychological suffering is not amongst other things, diagnosis related, ie iatrogenic. This is important and a good thing. this conferred responsibility can avoid confusion and If it is iatrogenic in nature which most experts believe is treatable, treatment should follow in order to proceed with the assessment That this be documented in writing of course, to promote transparency, accountability goes without saying.

- (2) Be linked to an advanced state of irreversible decline in capability of a patient suffering from the illness

This should be **Applied to a contemporaneous request as well, however I wish to highlight the benefit with regard to evaluating psychological suffering.** This will prevent exploitation of criteria 26 (4) that is presently occurring. The illness that is incurable is oftentimes not at an advanced state but the criteria is read to mean that the psychological suffering is advanced as it profoundly affects capability. Ostensibly in all intense and purpose this reduces the rigouersness and criteria burden as it was designed and intended. Criteria (4) and (5) as are no longer distinct criteria. Here all the people who can still walk but with difficulty, see but with difficulty or can no longer read can qualify yet many people function with these same limitation. If you remember Monettes case and another I **read** about they reported they could not longer read, had difficulty walking albeit they would also lose more cognitive faculties in time but MAID was applied . He did not want to continue on. He had recently lost his wife too . So the psychological suffering seemed to take precedence versus the advanced state of loss

for the neurodegenerative that was diagnosed. Did they simply ignoring one of the criteria altogether.(4) Or look at incorrectly the psychological suffering was resulting in reduced capability the Priddles case found in the appendix

“affects his speech, his ability to swallow and it makes walking laborious and slow. Once a world traveller with his wife Priddle is now largely housebound.”I think of it as my world is shrinking.” Obviously there is more here than was reported but it makes you question .”

(3) Be objectifiable for a competent professional who would have to observe the suffering before administering medical aid in dying.

Applied to a contemporaneous request as well, however I wish to highlight the benefit with regard to evaluating psychological suffering but slightly modified to read “be objectifiable for all competent professionals to observe and **document** prior to approving the request. Everything should be documented.(I forgot to mention in in 1 and 2)

CRITICAL TERMS IN CRITERIA DEFINITIONS

When filing either type of request for MAID one must be **capable of giving consent.**

Severe anxiety and clinical depression, even severe depression can affect capacity to consent. Iatrogenic depression oftentimes accompanies serious incurable diagnoses. These affective conditions should punctually and **preferably** be addressed by the care team, **at diagnosis** and it should be so **mandated** .These should include early counselling and consults with ergotherapist to make use of adaptive devices that can increase autonomy and prolong it and medications to control anxiety and depression.It will aid in

prevention of other complication, facilitate adaptation to the diagnosis and living in safety and security.

If these best care protocols are not mandated and fail to take place then they can affect the MAID process . If the patient arrives to make a request for MAID not having had these affective disorders attended to, efforts to assess whether they affect capacity to consent must be addressed. The testing and assessments must be **documented with treatment to follow documented as well** irregardless to whether or not they affect consent .

Addendums in Bill 38 distinguishing two types of requests should be questioned as to where or not there are benefit or needs. I do not see it as necessary.

The withdrawal of an contemporaneous request should proceed like an Advance Request, assistance may be required to assess capacity to consent as even a contemporaneous request still takes 90 days

I reiterate the importance of applying amendment 29.2 (1) (2) (3) to both contemporaneous and advance, It maintains the rigouressness and integrity of all criteria being distinct and applied.

I do not think that is necessary either that the advance request be filed in the directory. It being sent to the **patient file** is adequate particularly if it is centralized QHR .Updates should be as easy there as in the directory, either way they have to get there and into the patient file.

Advanced state of decline must be better defined as well with regard to **Alzheimer's**

What is crucial is that some consensus be reached to clearly define what constitutes an 'advanced state' within this law so the interpretation will not be left to a myriad of physicians not specialized in Alzheimer's or simply those who are loosely adhering

to the law's principles.(Federal Maid requires the competent professional to consult an expert in the field of the incurable disease which I think is much better) Classifications exist already and arguably it is difficult to place a person with Alzheimer's into a specific stage as stages overlap. However particularly Early-stage Alzheimer's (mild) and even Middle-stage Alzheimer's (moderate) must be examined carefully to decide whether either meet the criteria 5 of the Act respecting end-of-life care Section 26, (old version) that which states:

.... 5.Be in an advanced state of irreversible decline in capability.

Some barometer must be more clearly defined or there can be no adequate protection nor any transparency and accountability nor uniformity

Similar barometric measures must be defined for other diseases.

However it remains difficult regarding **advance request** descriptions for **later stages** according to this expert ,and I must apologize for losing the source of this text

"While the initial manifestations of the disease are often characterized by short-term memory loss, other symptoms appear **over time** and according to the individual. These symptoms vary and take many forms: impaired reasoning, lack of judgment, language disorders, visual-spatial dysfunction and behavioural disorders such as wandering or agitation. Two individuals who have this disease and have reached the same stage may therefore find themselves in diametrically opposed situations. One could show signs of aggression on a constant basis, while the other could be in a relatively serene and tranquil state. Under these conditions, it would be difficult to formulate an advance request for medical aid in dying in an informed manner. The person making the request would not know precisely what symptoms would occur and in what order they would appear."

All request amendments must specify the necessity of clearly communicating at the outset to the person making the request that only when an advanced state as well as the other criteria required and specified have been determined as being met, will the Request be executed. False expectations during say a 90 contemporaneous request can be detrimental to the psychological health and adaptation of the patient during the waiting interval.

Tolerable is a problematic concept as it relates to **psychological suffering** because it seems to be manifestly related to adaptability, expectation disillusionment . Rather than accept a patient's refusal to medicate as a method to alleviate psychological suffering if they find this **intolerable to the patient**, a conditional clause could be asserted that if the psychological suffering and anxiety is treatable your refusal to accept reasonable treatment will preclude the MAID eligibility ; as previously mentioned psychological treatment can impact on capacity to consent and as well as prolonging autonomy.

Persistent and unbearable. Must be **quantified and documented** otherwise it will be ignored and become insignificant and criteria rigour compromised. The physician is mandated to verify this periodically and each time should be **documented** and dated.

Regarding the physician

How will the competent professional **ascertain** the requests, either type are **freely made** and not the result of external pressure.

MAID provider handbooks could indicate warning signals to watch for but they are not always consulted. For so crucial a component a more exhaustive **checklist on the request form itself** itself should be **mandated and not filed until the 2nd professional also confirms it.**

moreover as MAID becomes more and more prominent it is important that society does not exert external pressure. For example

As reported by TVA October 27 Ministre Blais announced funding for caregivers which include "Des sommes sont aussi prévues pour **mieux former les proches aidants, par exemple sur des enjeux juridiques ou sur l'aide médicale à mourir**". Advocated, promoted and now funded and already existant in other community groups' initiatives, the explicit advising of caregivers of the option of MAID is important.

However it must remain the **Doctor's responsibility at diagnosis to present MAID as an option** amongst other alternatives to the patient and it must be made clear to caregivers whose incredible bond intensifies with dependency and loss of autonomy holds incredible influence, like an only child can that they must leave the decision to the patient. Caregiver groups must stress this as well.

Employees of all institutions, palliative care homes now where this information must be available must not express their own beliefs if they enter into a discussion.

The trusted third party responsible for advocating the advance request for medical aid in Dying **must not express their own beliefs** concerning medical aid in dying at diagnosis if present, or anytime thereafter lest they be perceived to exert influence on the person making an Advance request, and **should be obliged to consent to that in writing** on the same form the commission has dedicated to the trusted third party. Discussions are important but they are had to help **the patient** clarify **their** feelings on MAID.

informing the patient of the prognosis for the illness and of other therapeutic possibilities and their consequences should also be on the check list of the request form

Discussion with care team and patients close relations if wished for, must be documented and dated and the opportunity to discuss requests with other persons they wish to contact as well

Obtain the opinion of a second physician confirming that all criteria set out have been met. First competent professional should **sign something declaring** that everything relevant and impactful to a request for MAID has been included and sent to the 2nd physician, that he is providing all information he received, all queries, complaints.

Here it is important that the 2nd physician redo the work for himself and not just check it off on the first physicians evaluations . he must document this independently, record, consult, examine patient provide opinion in writing.

Then they Send to family physician duly completed .Requiring a **confirmation** of receipt by family physician will ensure it is entered in the patient file, if not done remotely by the assessing professional.

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The FOURTH DEBATE: THE DISCRIMINATORY APPLICATION OF MAID REVOLVING AROUND THE LACK OF RESOURCES MUST BE AVOIDED: ALL SUCH CASES MUST BE DOCUMENTED TO ENSURE THAT

One of the guiding principles from the select committees recommendations and upon which this bill is founded claims the following:

"..., it was noted that access to care and the implementation of a potential advance request are two different debates. Even with the best care and treatment, a person diagnosed with a neurocognitive disorder **should have the possibility of choosing his or her end of life**. Moreover, waiting until access to quality care is perfect before allowing an advance request would be tantamount to writing off that possibility. As Dr. Judes Poirier mentioned, there is always room for improvement when it comes to care.

In light of the demographic situation and the aging of Québec's population, the prospect of implementing advance requests would thus be continually postponed."

Longterm care and other support services must improve as it is a significant factor that is indeed contributing to many choosing MAID. Some people want to live with certain conditions but not if they will be neglected and abused,...that is a very sad state of affairs. Furthermore our Health care system is very fragile and overwhelmed now and for quite awhile to come in the aftermath of COVID delestage and avoided medical interventions. This with the rapidly aging demographics and no access to a family physician notwithstanding recent efforts, does not augur well.

Therefore if it becomes more and more likely that a lack of timely services can possibly **derail** the MAID Assessment process in many ways then it is not two separate debates. Furthermore it can impact on the voluntariness and informed consent criteria.

We see first from the Canadian government acknowledgement of the important of accessing services required for the compliance and viability of the MAID process to governing principles, albeit their acknowledgement is without teeth nor documented.

- 1. "The Canadian government even conceded in the CPSO Advice to the profession: medical assistance in Dying May 2021, the federal government has noted that the federal legislation does not specify a timeline within which the referral to these services and or treatments must take place. If the individual expresses interest in accessing services and or treatments which may relieve their suffering, but it will take significant time to access them the federal government advises MAID providers to take **great care** in assessing the **voluntariness and informed consent of the individual's request for MAID** if they proceed as a result of the **length of time it is taking to obtain those other services and or treatments.**"

- **2.Lack of resources** required to assess and-or provide alternative therapies to relieve suffering etc constitute prejudicial, non uniform injudicious and discriminative application of MAID which must violate some universal principle, but it most certainly is not fair.
- It could even possibly be criminal should in the filing of a MAID application and the evaluation ,the professional knowingly falsifies a statement...if he checks it off as unrelievable suffering when it not but rather a function of availability services or his lack of rigouressness in the pursuit of available. That is why it is important to document why he concludes it is unrelievable and what resources he has used to ascertain that

LACK OF RESOURCES, REAL OR PERCEIVED, ADDRESSED OR
IGNORED,PATIENT OR ASSESSOR

Excerpts from the articles in appendix

The "irremediable suffering" that qualified her for a medically
assisted death was **fixable**,
discussed her suffering, not solutions.

**"During the assessment, very little was focused on what services I had,
what I needed to achieve some level of normal. Nothing was offered in
terms of support,**

APPENDIX

CASE 1

POLICE INVESTIGATING MEDICALLY ASSISTED DEATH OF B.C. WOMAN

AVIS FAVARO CTV NATIONAL NEWS MEDICAL CORRESPONDENT

Police in Abbotsford, B.C. confirm they are investigating the medically-assisted death of a 61-year-old woman whose **daughters say should not have been approved for the procedure based on the state of her mental health at the time.**

The case involves Donna Duncan, a nurse and mother who died on Oct. 29, 2021. It appears to be among the **first assisted-death cases being reviewed by a police unit in Canada**, *although federal officials don't keep statistics on when such cases are reported to police.*

Her daughters, Alicia and Christie Duncan, say they requested a police investigation after what they claim were troubling circumstances around their mother's case that **raise questions about why she was approved for medical assistance in dying (MAID).**

"I don't want this to ever happen to another family ever again. And ultimately I **want stronger laws and legislation**," said Alicia.

Duncan was a long-time psychiatric nurse, described by her daughters as "happy" and "very enthusiastic about life." The daughters say that, despite previous health problems including breast cancer, she never suffered from anxiety or depression.

On Feb. 25, 2020, Duncan was in a car accident, near her home in Abbotsford. The following day at a walk-in clinic, she was diagnosed with a concussion.

But as COVID-19 restrictions were implemented across Canada, her daughters say her medical care and rehabilitation were curtailed.

"It was March and that's when the COVID shutdown happened. So she didn't have treatment for months and months," said Christie.

Medical documents obtained by the sisters and shared with CTV News also show that Duncan complained about headaches, bright lights, and difficulty concentrating, watching TV, or using a computer. In July 2020, she was identified as having post-concussion syndrome. Her daughters suspect the problems were compounded by stay-at-home orders during the pandemic.

"She was acting very strange and very out of character for her and was more irritable," said Christie. They also said Duncan began losing weight. Documents show her family physician, Dr. Parin Patel, was noting she had low mood, anxiety and depression, likely linked to the car accident. Notes show Duncan agreed to start seeing a counsellor on Nov. 3, 2020.

The daughters say Duncan **was prescribed medication but rarely took it for long periods.**

"So she would try it for one day and say, 'Oh, if that one doesn't work, I'm not going to take that. Oh, yeah, the antidepressants don't work,'" said Alicia.

For over a year, the daughters say Duncan underwent many tests to determine the source of her pain and weight loss but no physical cause was identified. Duncan herself suggested she might have Central Sensitivity Syndrome (CSS), a pain-related condition. Physical trauma like a car accident is considered a possible trigger.

Documents show that Patel referred Duncan to a clinic at B.C Women's Hospital that specializes in pain syndromes. But Duncan's daughters say **she never went to the appointment** and so was never formally diagnosed with CSS.

In early October, a psychiatrist in Abbotsford, Dr. Shah Khan, saw Donna and reported in medical records that while the source of her physical problems was unclear, a somatic disorder was likely part of the picture. This condition causes an extreme focus on physical symptoms such as pain that cause emotional distress. **Treatments include therapy, antidepressants, and treatment by a specialist in mental health, according to the Cleveland Clinic.**

'CONCERNING CASE'

By October 2021, the situation turned into a crisis.

Weighing just 82 pounds, Duncan kept losing weight and was using a walker. Her common-law partner, Rick Hansum, said she had been suffering for months and was rapidly losing weight despite consuming 1,500 calories a day.

"She couldn't wear clothes because they hurt. Pureed food and shakes felt like broken glass. People don't realize the pain she was in," Hansum told CTV News in a phone interview.

Duncan asked Patel to approve her for a medically-assisted death, telling him she had a poor quality of life, according to medical records. He declined. In medical notes provided to **CTV News by Duncan's family, he wrote that her "mental health really needs to be treated" and that she had only tried a couple of anti-anxiety medications, which she discontinued.**

She was referred to a psychiatrist, Dr. Abid Khattak, who on Oct. 14 told Patel he believes the **depression is related to her illness over the past one to two years and her refusal to "take any medications."**

The notes from Khattak also say **"her feeling that this is all physical is so strong that unless she is made aware** that treating the mental health condition is a process and takes time...it would take weeks to months to realize the improvements."

Several **psychiatrists'** names were suggested for follow-up care in the visit record, but Duncan ultimately went to B.C.'s Fraser Health to seek MAID.

Alicia and Christie say they didn't learn of their mom's plans for a medically-assisted death until Oct. 22, when Duncan texted them to say she had been assessed and approved by one MAID practitioner with Fraser Health: Sean Young, a nurse practitioner. The second approval was from Dr. Grace Park, a MAID practitioner also with Fraser Health. **Park visited Donna in person on Oct. 24** and signed the second approval.

MAID laws in Canada require two health practitioners to approve someone for a medically-assisted death. There are criteria doctors or nurse

practitioners must follow, **including discussion of whether other measures to treat the patient's illness have been taken.**

With the two signatures, Duncan's death was scheduled for two days later, on Oct. 26.

At that point, Alicia and Christie say they went into panic mode.

"She said, I've been approved.... and she said, 'yes in 48 hours' and I just started crying and was in complete shock," said Christie.

The daughters obtained a **court injunction halting the procedure and were granted a mental health warrant allowing police to take their mother to the emergency unit at Abbotsford Regional Hospital.**

A psychiatric consult on Oct. 26 by Dr. Zia Ui Haque said he "saw no convincing evidence of depression (or) anxiety" and deemed Duncan competent to make the choice "even though she may be making an unwise choice about medical assistance in dying." He also noted that she had "not explored other avenues including pain relief or any other medical intervention," according to the consultation document shared with CTV News.

That night at home, Hansum found her on the floor with a **"lacerated" left wrist, which sent Duncan back to the hospital for stitches.**

On Oct. 27, she had another psychiatric assessment by Khattak who found Duncan **"in distress," said that her mood was "depressed" and that she had "limited insight into her problem."** She agreed to a transfer to another hospital in Chilliwack, telling doctors she was embarrassed being in the Abbotsford hospital, having worked there as a psychiatric nurse.

At the second hospital, doctors again assessed Duncan and determined she was not depressed, and cleared as competent. She was released from hospital on Oct. 29 at 4:30 p.m.

Alicia and Christie say that around 9:30 the same night, they received a text from Hansum with the message their mother had a medically-assisted death at home, according to her wishes.

"I believe Donna had the right to make the choice she did," Hansum told CTV News. "Her decision for MAID was not an easy one. But she was comfortable with the decision once she made it."

The death certificate shared with CTV News shows that while MAID was listed as Duncan's cause of death, **Central Sensitivity Syndrome is the underlying cause or reason, noting that she had suffered for 18 months. However, the daughters argue their mother had never been formally diagnosed with CSS and had never seen a doctor for treatment of this condition in part because of long wait times, and because her family doctor said the underlying depression and anxiety needed to be treated first.**

The death certificate also says Duncan suffered from frailty and cachexia, a wasting disorder. Her daughters requested an autopsy to see if there was another underlying disease, and say **they still don't have a copy of the results.**

"She hasn't been properly assessed. I really felt that had she been forced to take antidepressants..... I think our mom would be alive," said Alicia.

"If my mother had not been suffering from mental illness, she would [not have] thought this. She is a two-time cancer survivor. She would have survived this, but she was not in a place mentally to be able to make that decision subjectively," said Christie.

Alicia and Christie took their case to Abbotsford police. Officials have been looking at the case for nearly two months, according to information received by the daughters. Police declined to comment on their investigation or on whether any charges will be laid.

"I ask that you allow the investigative team a chance to follow the evidence in this case and give them time to do that. These types of investigations are very complex and take a significant amount of time to complete," Const. Paul Walker, media relations officer for Abbotsford police, wrote in an email to CTV News.

CTV News also contacted several doctors involved in this case. Dr. Parin Patel, Duncan's family physician, declined to comment.

The two health professionals who approved Duncan's assisted death – nurse practitioner Sean Young and Dr. Grace Park -- also did not respond.

In an email, a spokesperson for B.C's Fraser Health wrote that the health authority offers "condolences to the family." Fraser Health "abides by

current federal legislation which states that Medical Assistance in Dying is provided only to legally eligible patients," the spokesperson said.

"This is a concerning case," said Trudo Lemmens, a University of Toronto law professor who is also studying MAID in Canada and the country's plans to expand assisted death to those with mental illnesses in May 2023.

"The speed by which this happened is concerning," he said, pointing to the fact that Duncan's assisted death was scheduled just two days after approval.

The case also raises questions about conflicts in families around the time of MAID requests. **It has arisen in other cases, like that of Alan Nichols,** whose family members discovered two days in advance he was approved for a medically-assisted death and questioned the medical decision-making for a man who refused to take medications for mental illness.

Alicia and Christie have set up a petition and fundraiser hoping to tighten laws around the approval of medically-assisted death. **They want better safeguards, along with ways that families can participate in MAID assessments.**

"There (are) too many gray areas that are allowing doctors to end people's lives instead of treating them," said Christie.

Lemmens said their case offers a wider lesson on the need for a better way to review MAID cases that include families in a decision that is so final.

"We need to reflect on how to address the concerns of family members who lose loved ones in MAID procedures that appear to disregard patients' complex physical and mental health situation and **without having tried all other options to relieve their suffering," said Lemmens.**

CASE 2

WOMAN WITH DISABILITIES APPROVED FOR MEDICALLY ASSISTED DEATH RELOCATED THANKS TO 'INSPIRING' SUPPORT

AVIS FAVARO CTV NATIONAL NEWS MEDICAL CORRESPONDENT

A 31-year-old disabled Toronto woman who was conditionally approved for a medically assisted death after a fruitless bid for safe housing says her life has been "changed" by an outpouring of support after telling her story.

"It's ... mind-blowing and inspiring," said Denise, in a phone interview.

Her voice sounded considerably stronger than in April when [she last spoke with CTV News](#) about her pending approval for MAID, a decision she said she made, in part, because she was suffering from severe chemical sensitivities in an apartment filled with smoke and fumes that made her ill.

She told CTV News at the time that she had spent months trying to secure housing with cleaner air and essentially gave up and was cleared by two doctors as qualifying for an assisted death.

But now she's found a temporary home, is no longer struggling for every breath and her extreme suffering has lessened, her application for MAID is on pause. However, Denise says she has not cancelled the MAID application outright as she still has several other pain-causing chronic health issues that haven't been properly addressed.

After the story, which garnered worldwide attention, supporters set up a GoFundMe campaign that has now has amassed over \$65,000 in donations from nearly 1,000 people along with countless emails of encouragement.

"These are strangers saying they do not want this to happen. I am even struggling to find the words," Denise said.

She says she is now living in a hotel room in Toronto that uses low-scented cleaning chemicals, and has windows that open on a ravine, providing fresh air.

"I am no longer focusing on just survival," she told CTV News. "Mentally, I am more clear to put things in place to put a more liveable life."

She is working to find long-term subsidized housing and is hoping to help others with chemical sensitivities.

The "irremediable suffering" that qualified her for a medically assisted death was fixable, said Dr. Riina Bray, the medical director of the Environmental Health Clinic at Women's College Hospital in Toronto, and one of Denise's physicians.

"It says these patients can easily return to wellness if they are given the right environment to live. It's a simple equation," she said.

Denise, who asked CTV News not to use her real name to protect her identity, was diagnosed with Multiple Chemical Sensitivities (MCS), which trigger rashes, difficulty breathing, and blinding headaches.

Research shows that people with multiple chemical sensitivities often improve in chemically cleaner environments.

She is also a wheelchair user after a spinal cord injury six years ago.

But her only income comes from Ontario's Disability Support Program (ODSP) which pays \$1,169 a month plus \$50 for a special diet. That made it impossible for Denise to pay for a better apartment away from smoke and chemicals.

When repeated requests for subsidized apartments in healthier locations went unanswered by housing officials she applied for MAID, "essentially, because of abject poverty," she told CTV News in April.

She was approved by two doctors and was asked for documentation on funeral preparations by a third.

Denise's supporters are calling for a closer look at how and why she was approved for MAID when what she needed was housing that didn't aggravate her symptoms.

"We're calling for an investigation into physicians who are improperly applying the (MAID) legislation," said David Fancy a professor at Brock University and one of Denise's supporters.

Denise says the doctors who offered medical assistance in dying discussed her suffering, not solutions. "During the assessment, very little was focused

on what services I had, what I needed to achieve some level of normal. Nothing was offered in terms of support," she said.

The Well Earth collaborative, which is fundraising for Denise, is also applying to the Canada Mortgage and Housing Corporation for funding to build special housing for others with environmental sensitivities, with a 50-acre plot of land in a rural region north of Toronto identified as a possible site.

Multiple Chemical Sensitivities (MCS) is a recognized disability under the Canadian Human Rights Act. It's believed to be caused by exposures to chemicals, or other environmental exposures that cause physical symptoms, although it is a controversial diagnosis in the medical community.

Her story is disturbingly similar to one reported by CTV News earlier in April. Sophia also suffered from Multiple Chemical Sensitivities. She [received a medically assisted death in February](#), after many attempts to get an apartment away from the smoke and chemicals in her building.

Canadian statistics suggest that at least 700,000 people in the country suffer from sensitivities to chemicals.

CASE 3

WOMAN WITH CHEMICAL SENSITIVITIES CHOSE MEDICALLY-ASSISTED DEATH AFTER FAILED BID TO GET BETTER HOUSING

AVIS FAVARO CTV NATIONAL NEWS MEDICAL CORRESPONDENT

A 51-year-old Ontario woman with severe sensitivities to chemicals chose medically-assisted death after her desperate search for affordable housing free of cigarette smoke and chemical cleaners failed, advocates say.

The woman's assisted death appears to be a first in the world for someone diagnosed with multiple chemical sensitivities (MCS), a chronic condition also referred to as an environmental illness or environmental allergies, say patient support groups and doctors familiar with her case.

"The government sees me as expendable trash, a complainer, useless and a pain in the a**," 'Sophia' said in a video filmed on Feb. 14, eight days before her death, and shared with CTV News by one of her friends.

She died after a frantic effort by friends, supporters and even her doctors to get her safe and affordable housing in Toronto. She also left behind letters showing a desperate two-year search for help, in which she begs local, provincial and federal officials for assistance in finding a home away from the smoke and chemicals wafting through her apartment.

CASE 4

EXTRACT FROM ARTICLE

A RARE LOOK AT CANADA'S GROWING DEMAND FOR MEDICAL ASSISTANCE IN DYING

AVIS FAVARO CTV NATIONAL NEWS MEDICAL CORRESPONDENT

In March 2021, a second group of patients were granted the right seek assisted dying. According to the new legislation, people with serious and incurable illnesses or disabilities, but who aren't actually dying, are allowed to ask for death.

Sixty-nine-year-old John Priddle is an example of one of these cases, called Track Two cases.

Unlike Ray Cole who is *dying* of cancer, Priddle has a chronic and progressive neurological disorder called Friedreich's Ataxia. It affects his speech, his ability to swallow and it makes walking laborious and slow. Once a world traveller with his wife Jacqui, Priddle is now largely housebound.

"I think of it as my world is shrinking."

A small but growing proportion of patients on Vancouver Island are Track Two cases. Dr. Green has approved a few. But she cautions that in order to qualify people have to have been offered -- and seriously considered -- all care to alleviate their suffering.

Dr. Green assures him that considering all the factors, including John's 20 years of treatments that failed to stop the progression of his disease, should the time come when he asks for help to die sooner, he would get approved for MAiD.

"There's a chance you might live many more years, and you'll excuse me for saying, die from something else," she told him.

"It's going to sound really weird, maybe to some, but I think it makes me feel quite a bit relieved," Priddle told W5.

Only 4 per cent of assisted deaths on Vancouver Island were Track Two cases last year – those who are not imminently dying. It's a small number.

But it's still much higher than in Ontario, where Dr. Scott Anderson say he and his colleagues have been much more reluctant to approve any Track Two patients because of the complexities of those cases.

"If you look at chronic pain, sometimes the main problem may not even be chronic pain. The main problem may be mental health issues where they have suffered from depression, hopelessness -- just a whole litany of things that come with chronic pain," said Dr. Anderson.

"Sometimes these patients are vulnerable because they haven't been able to get proper pain management or homecare services. They express a wish to die. But really, if you flush it out, a lot of them don't want to die."

There's one patient who stays with Dr. Anderson, even though the man was approved for MAiD as a Track One case.

"He came to me with depression, a neurologic condition, a variety of other problems, social problems. I did feel he qualified."

But on the day of his procedure. He didn't show up.

"When I tracked him down, he said he was very sorry. But he was at a job interview and couldn't make it," said Dr. Anderson.

"It tells you that a patient's desire or frustrations or requests for MAiD can fluctuate over time. Once a MAiD has been performed, there's no going back. So, if we should be anything, we should be overly careful."

Dr. Green said she's fully aware of the pitfalls and the variations across the country.

That's why she helped found the [Canadian Association of MAiD Assessors and Providers](#). One of the group's goals is to standardize assessments and care across the country. With that in mind, Dr. Green is about to launch the first educational program in Canada for doctors and nurse practitioners interested in providing assisted death.

She hopes the program will help alleviate some of the regional differences.

"A Haligonian in Halifax who wants to have MAiD, who has a certain diagnosis and wants to seek an assessment, is treated with the same type of approach and expertise as someone in Manitoba or British Columbia. I think that's essential," said Dr. Green.

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OPINION: ADVANCE DIRECTIVES FOR ASSISTED DEATH A RECIPE FOR ABUSE

CATHERINE FERRIER FOR THE MONTREAL GAZETTE

The prospect of facing dementia evokes dread.

In my work in geriatric medicine, I have cared for thousands of people with dementia and their families. The challenge they face is not only the disease, but the stigma and neglect. The constantly fuelled perception that their life is undignified. Inadequate home care services. Family caregivers isolated and burning out. Residential options unavailable, too expensive or too rigidly structured to meet people's needs. Fear of CHSLDs since the COVID pandemic.

In my work in geriatric medicine, I have cared for thousands of people with dementia and their families. The challenge they face is not only the disease, but the stigma and neglect. The constantly fuelled perception that their life is undignified. Inadequate home care services. Family caregivers isolated and burning out. Residential options unavailable, too expensive or too rigidly structured to meet people's needs. Fear of CHSLDs since the COVID pandemic.

Our society is not interested in people with dementia. That is discrimination. But instead of addressing it [through education, family support](#) and increased government support, we seek a quick fix, a tool to escape dementia.

That tool is the advance directive for "medical aid in dying" (MAiD), something [the bill introduced Wednesday](#) by Quebec Health Minister Christian Dubé would permit.

I am regularly involved in legal disputes surrounding my patients. Is the will signed in the hospital three days before death valid? What about the protection mandate entrusting personal and financial decisions to an abuser?

The most public case in my career was chronicled in the Montreal Gazette: [Veronika Piela](#), an elderly widow with no children, was forcibly removed from her home and had her bank account emptied, on the basis of a protection mandate later found to be forged. The crime would have been one of many that pass under the radar, had she not fled a nursing home without a coat in February.

Such are the limits of written documents.

Advance directives were invented to allow advance refusal of high-technology medical interventions expected to be futile or excessively burdensome. They are a request to be left alone, to not be touched. If one dies after treatment is refused or withdrawn, it is through the natural progression of the illness. An advance request for MAiD, on the other hand, is asking for an active intervention to end life. The important ethical distinction between these acts is often blurred in the current debate.

In the 50 years since the first advance directives for treatment refusal, advance care planning has evolved considerably, and now emphasizes a reflection and communication process throughout an illness, including discussion of broad life and health-care goals, and naming a substitute decision-maker. Documents alone are seen as inadequate and a last resort. This is for two reasons.

On the one hand, informed consent requires full knowledge of the condition for which an intervention is being considered, which is not possible in advance. On the other, research shows that people change their minds as an illness progresses, and later choices are very different from those they would have made when they were well or in the early stages of the disease. That is true also with dementia.

The 2018 Council of Canadian Academies Expert Panel on Advance Requests for Medical Assistance in Dying [studied in detail the literature](#) on advance care planning. They found very few studies looking at written directives alone, and no evidence that they affected meaningful outcomes. In one Canadian study the documented preferences did not match the expressed wishes of the patient 70 per cent of the time.

End-of-life experts now express serious doubts about the utility of written advance directives for treatment decisions. But the Quebec public is wildly enthusiastic about using them to request death.

This is very alarming.

Legalizing MAiD by advance request means, in stark simple terms, that doctors will kill people who are not asking to be killed. Some will resist and will have to be sedated without their knowledge or held down to inject the poison. That is what happens in the Netherlands now, and it has led to grave concern and decreasing support for the practice, even among those in favour of euthanasia for consenting adults.

Far from being the ultimate act of autonomy, MAiD by advance directive is a recipe for elder abuse.

Catherine Ferrier is a Montreal physician.

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STAKEHOLDERS POSITION CITED IN SELECTION COMMITTEE REPORT

The issue of access to quality health care for persons with neurocognitive disorders was raised several times during our deliberations, particularly by **stakeholders** who opposed advance requests. Indeed, some of them mentioned that care for the elderly has been underfunded over the years. This lack of funding has allegedly hindered access to resources, but also affected the ability of the health and social services network to provide care adapted to their needs. Yet, this type of care is very important for persons with neurocognitive disorders. It should be noted that they can no longer express their needs or discomforts clearly. It is therefore essential that the care team be able to spend time with each individual. The goal is to recognize their signs of discomfort, respond appropriately to their needs and, when necessary, try different treatments **to ease their suffering. In the absence of such care, many stakeholders stated that it would be premature to offer the possibility of making an advance request for medical aid in dying. Some people might then be tempted to make such a request for lack of a better option, anticipating the lack of care.**