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# Special Joint Committee on Medical Assistance in Dying

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Co-Chairs:  
The Honourable Marc Garneau The Honourable Yonah Martin





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• (1830)

[*Translation*]

**The Joint Chair (Hon. Marc Garneau (Notre-Dame-de-Grâce—Westmount, Lib.)):** I call the meeting to order

Welcome to meeting No. 26 of the Special Joint Committee on Medical Assistance in Dying.

I'd like to welcome members of the committee, witnesses, and those watching this meeting on the web.

[*English*]

My name is Marc Garneau, and I am the House of Commons joint chair of this committee.

I am joined by the Honourable Yonah Martin, the Senate's joint chair.

Today we are continuing our statutory review of the provisions of the Criminal Code related to medical assistance in dying and their application.

I have a few administrative points to make. I'd like to remind members and witnesses to keep their microphones muted unless recognized by name by one of the joint chairs.

I will also remind you that all comments should be addressed through the joint chairs.

[*Translation*]

When speaking, please speak slowly and clearly for the benefit of the interpreters.

Interpretation services are available for people participating in the meeting both by videoconference and in person. People participating remotely have the choice, at the bottom of their screen, between floor, English and French.

[*English*]

With that, I would like to welcome our witnesses for panel one, who are here to discuss mature minors.

As individuals, we have present with us Dr. Dawn Davies, pediatric palliative care physician, and, appearing remotely, Cheryl Milne, executive director of the David Asper Centre for Constitutional Rights. As well, from The Hospital for Sick Children, we have Randi Zlotnik Shaul, director of the department of bioethics.

Thank you, all three of you, for joining us tonight.

We'll begin with opening remarks, followed by questions for the panellists. These are five-minute opening remarks, and I'd like to start with Dr. Davies.

Dr. Davies, if you're ready, you have five minutes for your opening remarks.

**Dr. Dawn Davies (Pediatric Palliative Care Physician, As an Individual):** Thank you. I think mine will be somewhat less than that.

I'm hoping that what I can share with you tonight are some of the practical experiences I've had in the last 25 years or so working with children, families and youth as a palliative care physician for children. Also, I was the chair of the CPS, the Canadian Paediatric Society, bioethics committee when the Carter decision was made, and I was the author of the CPS position statement, "Medical Assistance in Dying: A Paediatric Perspective", with respect to mature minors.

I look at all my learned colleagues who have presented to you before me and who will after me, but I am hoping that somehow you've been able to hear the voices of children and families who are affected or have been affected by these issues. I can think of so many families who I think would lend a critical lens to this discussion, and I hope you've been able to find them.

I'll curtail my remarks to that for the time being.

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Dr. Davies.

With that, we'll now turn to Cheryl Milne, executive director of the David Asper Centre.

You have five minutes, Ms. Milne.

**Ms. Cheryl Milne (Executive Director, David Asper Centre for Constitutional Rights, As an Individual):** Thank you very much, and thank you for inviting me to this hearing.

In addition to being the director of the David Asper Centre, I am a practising lawyer. I have spent many years representing young people at the legal clinic, Justice for Children and Youth, including as an intervenor in the seminal case from the Supreme Court of Canada, *A.C. v. Manitoba*, so my background includes some knowledge in terms of how the law works with respect to medical decision-making for children.

The Supreme Court of Canada said that a mature young person should be able to make these kinds of decisions, even if the decision has grave consequences, if they have the capacity to do so.

For example, there is legislation across the country that varies in terms of how the young person can make these kinds of decisions. In legislation that articulates a best-interest standard, for example, which occurs in some provinces, that standard should be interpreted so that the choice of an independent minor capable of making decisions must be respected.

In addition to the Supreme Court of Canada, that decision was based upon the Charter of Rights and Freedoms, section 7.

The court also based the decision on the United Nations Convention on the Rights of the Child. The articles that are relevant are primarily article 12, which requires Canada to give due weight to a child's views in accordance with the age of maturity of the child, and article 5, which requires Canada to respect the responsibilities, rights and duties of parents to provide appropriate direction and guidance in the exercise of the child's rights in a manner that is consistent with the evolving capacities of the child.

There are also other articles that add complexity and nuance to those decisions. Article 2 deals with non-discrimination; article 6 is around the survival and development of the child, and article 24 is about access to health care and health services. These are all relevant when looking at the provision of MAID for young people under the age of 18.

In respect of safeguards, article 23 also requires the recognition that children with disabilities enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

One of my primary recommendations—and I think you've heard it before from other witnesses who have come before me—is the need to really address or listen to the voices of children and youth in these circumstances. I know other organizations have recommended something that's called a CRIA, a child rights impact assessment. A CRIA involves both consultation with experts, which we are doing this evening and which you have done up to this time, and also consultation with young people who are directly affected.

I won't go on. My speaking notes talk about different vulnerable groups that you need to specifically address.

I also want to say that in addition to talking to children and youth as a group and consulting with them, we have to remember that we can't really drag this out too long because, in the meantime, there are individual young people under the age of 18 who are potentially suffering and who are being denied this particular treatment so that their individual views and preferences are, right now, not necessarily being considered. While I think consultation with children and youth more generally is essential, we also need to think about the individual young people.

I'll leave it there, and hopefully I can answer more detailed questions for you.

• (1835)

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Ms. Milne.

We'll now go to our third witness, Randi Zlotnik Shaul.

Ms. Shaul, you have five minutes.

**Dr. Randi Zlotnik Shaul (Director, Department of Bioethics, Hospital for Sick Children):** Thank you, Mr. Chair. Thank you as well for the invitation to present to the Special Joint Committee on Medical Assistance in Dying.

In addition to being director of the department of bioethics at the Hospital for Sick Children in Toronto, I've worked as a pediatric bioethicist for more than 22 years. I am also an associate professor in the department of pediatrics at the University of Toronto.

With today's special panellists, I also had the honour of being a member of the Council of Canadian Academies MAID expert panel mature minors working group, and have collaborated with dedicated child and family-centred colleagues at SickKids and beyond, grappling with questions associated with MAID and mature minors.

A bioethics lens can be helpful when a decision has to be made and values at the heart of the decision may be pulling a decision-maker towards different choices. For such challenging issues in health care, the aim is to carefully and accountably consider all relevant information, relevant law, clinical evidence and ethics literature to make a decision that best reflects the values one considers most important, and to minimize resulting harms.

Through legal decisions from our country's highest courts and the checks and balances associated with enacting law, MAID is legal in Canada for those suffering from a grievous and irremediable medical condition, in an advanced state of irreversible decline, and experiencing enduring suffering where natural death is reasonably foreseeable and voluntarily requested by a capable person 18 or over, informed by the means available to relieve suffering.

From an ethics point of view, Canada's framework for MAID is supported by considerations of beneficence and nonmaleficence, the duty to provide benefit and avoid harm, and respect for autonomy and justice. At this point, the question seems to be, is there anything about MAID that should require a different approach from that which already enables mature minors to make other health care decisions for themselves, even those that may not extend life? Here, examples may include a mature minor opting for palliative care or declining yet another round of chemotherapy where it holds out very little chance of success.

In thinking through these answers, one can want to respect the autonomy of mature minors while also wanting to be confident that appropriate safeguards are in place. The current framework for accessing MAID has safeguards built into it that would apply to mature minors if access were expanded.

For example, to be found capable of consenting to MAID, a person must be able to understand what MAID entails and appreciate the implications to themselves of consenting or refusing the procedure. The implications of capacity being decision specific is that the more complex a decision and the more serious the consequences, the higher the level of cognitive development and maturity needed to be found capable of making the decision. These requirements are built-in safeguards, ensuring that only those who meet all the stringent requirements necessary for MAID and have the sufficiently high cognitive ability and maturity would qualify for access.

I would add two additional recommendations.

The first would be increased access to palliative care, so that it is available to all in need as a possible alternative to MAID. That being said, my understanding from outstanding and experienced palliative care colleagues is that in rare cases, even what palliative care has to offer may not be enough to address irremediable suffering in a way that is acceptable to the patient.

Finally, while the report of the CCA was excellent, working group members acknowledged that there was insufficient analysis of the views of young people related to MAID to feel confident that the perspectives of those most impacted by expansion of access have been considered.

Missing are perspectives of youth with a range of relevant life experiences: indigenous youth, youth living with disabilities, youth in the child welfare system and youth living with terminal illnesses, as well as their families. In keeping with the previous testimony from Franco Carnevale and Mary Ellen Macdonald, respecting our responsibilities to young people would include studying their perspectives and bringing their voices into deliberations about expanded access.

Thank you for the opportunity to share these considerations. I would be happy to do my best to answer any additional questions.

• (1840)

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Ms. Shaul.

We'll now go to questions, and I'll turn it over to the joint chair, Senator Martin.

**The Joint Chair (Hon. Yonah Martin (Senator, British Columbia, C)):** Thank you.

Thank you to all of our witnesses for your testimony this evening.

We'll begin the first round of questions with Dr. Ellis for five minutes.

**Mr. Stephen Ellis (Cumberland—Colchester, CPC):** Thank you, Chair, and thank you to the witnesses for being here.

I have been a family doctor for 26 years, just as full disclosure.

I'd like to start with Ms. Shaul, through you, Chair, if I could. You talked about having the opinions of kids from a variety of backgrounds, and certainly in the experience of this committee I don't think we've had the fullness of that discussion. How do you see that playing out in terms of delaying the decision-making with

respect to mature minors, with the caveat, of course, that we haven't had children appear at this committee?

**Dr. Randi Zlotnik Shaul:** I do think that's a concern, as was just mentioned by Professor Milne. A delay is not a neutral position. A delay is something that is significant, and it may be that otherwise eligible young people would not have access, so I think a balance needs to be established here. The challenge, though, is that going forward without these voices is really going forward with a potentially incomplete window into all issues that need to be considered.

So, with humility, we don't know what we don't know, and we don't know what issues or considerations might be raised. I'll leave it to this esteemed committee to decide how to balance that. Perhaps an option might be a staged expansion of access, whereby perhaps you expand it—and again, this is your decision in terms of weighing everything—to 16- and 17-year-olds now, with a stated timeline of when this would be reviewed—so it's not an indefinite re-review—once the more fulsome window into missing voices has been included.

I agree that it's not a neutral position just to indefinitely delay, but it is a concern to be moving forward with insufficient information.

Thank you.

• (1845)

**Mr. Stephen Ellis:** Thank you very much for that. I appreciate it.

Through you, Chair, Dr. Davies, something we didn't hear much about in anybody's opening statement today is how the decision-making of the parents plays into the role of mature minors. You've been a pediatrician in palliative care for a long time. Tell us a bit about your idea of an approach to decision-making and involving the parents with respect to mature minors.

**Dr. Dawn Davies:** That's tricky. In my experience with families, the child or youth and their parents are very often of the same mind. I've had a few encounters in which parents and their child had different opinions about what they wanted for treatment, but as the child's illness progressed, I can't think of a situation in which the child wanted one thing and the parents wanted something different.

With MAID in general, there are situations, sadly, in which the person who opts for MAID does not have the support or approval of their family. That may actually play out in the world of children and youth, but for the most part there will be concordance, and for the rare cases in which there isn't, I think that going with the decision of the mature minor, with all the caveats that Dr. Zlotnik Shaul just laid out, would be acceptable.

**Mr. Stephen Ellis:** Thank you, Dr. Davies, and through you, Chair, once more to Dr. Davies, this committee has heard a fair bit about palliative care availability, which is a significant issue in multiple places in Canada. Maybe you could talk about your experience with that.

To my mind it's a real issue for children—and adults, of course—and I guess some of the concern I have is related to the fact that people may choose MAID simply because they don't have good palliative care services available. Maybe you could comment on that.

**Dr. Dawn Davies:** I think that's true. However, if we look at adults who have opted for MAID, many of them have had excellent palliative care. I think I'm one of a minority of physicians in that I don't think that palliative care is the answer to the question about whether or not there should be MAID.

Obviously I'm passionate about providing excellent palliative care, but I can still think of families whose child was dying, who questioned why they must live in that state any longer. That might be an existential sort of concern, a physical symptoms sort of concern, and I think poignantly of one family I cared for recently, in which the child's mother had opted for MAID for cancer the week before the grandchild died, and the mother caring for this child, who was also dying of a malignancy, said, "Why can't we make this choice?"

Therefore, I think that the mature minors are one scenario and the parents of never-capable children are another one. I know that is not the purview of this committee, but it's actually the question that's raised to me more often than those from the youth themselves.

**The Joint Chair (Hon. Yonah Martin):** Thank you, Dr. Davies.

Next we'll have Mr. Maloney for five minutes.

**Mr. James Maloney (Etobicoke—Lakeshore, Lib.):** Thank you, Madam Chair, and thank you to all three of our witnesses. As is always the case, your testimony is very helpful.

Dr. Davies, I'm going to start with you on the palliative care issue. This issue has come up time and time again, mostly not in the situation we're discussing now with mature minors.... Everybody around this table and everybody everywhere agrees that we're in need of more and better palliative care, but should the fact that this ideal level of palliative care doesn't exist mean a full stop to medically assisted dying?

**Dr. Dawn Davies:** I don't think so.

**Mr. James Maloney:** Would your answer be any different in the context of mature minors?

**Dr. Dawn Davies:** No, because for families that want it, it is available. It might mean relocating as a family for a period of time, but it is available. In small communities, it's just how you build teams around that family. It might not be perfect, but....

**Mr. James Maloney:** You said something in response to Dr. Ellis about.... We were talking about mature minors and were talking about a situation that doesn't exist now; this is not available for mature minors right now. You made a statement to the effect that you've rarely—maybe never—seen a case in which when you get to a certain point, parents and child disagree on what the appropriate treatment is. Do you think that's a fair comparison to make in the context we're talking about right now? It's an entirely different decision: In my opinion, palliative care or other personal health decisions are—I'm struggling to find words—not as significant as the issue we're talking about here. Do you think that's a fair comparison?

• (1850)

**Dr. Dawn Davies:** I do think it's a fair comparison. When we look at lots of decisions mature minors might take, it might be earlier in the trajectory, but the outcome may be the same. If they de-

cide against further chemotherapy or further immunotherapy, or something like that, the outcome might be just as dire; it's just the moment in time the decision is taken. I think they're comparable, and mature minors, especially those who have lived with severe illness, are very well informed by their lived experience to make such a decision.

**Mr. James Maloney:** Okay. Thank you.

Let's take the scenario a step further, let's talk about a situation in which they don't agree and we're talking about MAID. What would you recommend that a doctor do in that situation, where the individual under 18 is deemed to be mature enough to make this decision, but the parents don't agree? What happens there?

**Dr. Dawn Davies:** I really think that if the youth is found to be mature and capable, there may be parents who can't accept the reality of that person's situation. I think it will be very infrequent, and I don't think that should be a barrier to what this committee recommends. Just like in the adult world, we should go with the decision of the person it's going to affect, which is the patient.

**Mr. James Maloney:** It may be infrequent, but it could happen.

**Dr. Dawn Davies:** It could, yes.

**Mr. James Maloney:** My question is what you do in that scenario. You're saying you go with the decision of the child.

**Dr. Dawn Davies:** If they were found to be capable, yes, I would.

**Mr. James Maloney:** Okay, thank you.

Dr. Zlotnik Shaul, you raised some concerns in your opening and with Dr. Ellis about the fact that we haven't had children testify before this committee. I think you said it's an incomplete window. Are you saying to us that we should not proceed with the recommendation that it's acceptable to allow mature minors to access MAID?

**Dr. Randi Zlotnik Shaul:** It's a hard call. It is a hard call.

Like I tried to say a moment ago, I don't think it should be an indefinite halt until there's the most fulsome review of the positions that are missed, and I'm wondering if perhaps a staged approach to increasing access might be a possibility. There's a lot of confidence in 16- and 17-year-olds having this comparable or potentially having the same comparable maturity and capacity as those aged 18. Again, this is vulnerable—and I'll leave that to Cheryl Milne to speak to—to legal challenge, because even allowing access just to 16 and 17 would be considered an arbitrary cut-off. Perhaps as part of a staged expansion you could do something like that, where it's not left with the barrier at 18—

**Mr. James Maloney:** I'm sorry. I'm running out of time. I apologize.

Should we do it now? Are we ready? That was the question.

**Dr. Randi Zlotnik Shaul:** Greater access than there is right now is ready, but it shouldn't be granted alone without a clear expansion of gaining perspectives that are missing.

**The Joint Chair (Hon. Yonah Martin):** Thank you very much.

Next is Mr. Thériault.

You have five minutes.

[*Translation*]

**Mr. Luc Thériault (Montcalm, BQ):** Thank you, Madam Chair.

I'm going to try to ask all three witnesses questions, starting with Ms. Zlotnik Shaul.

You are talking about expanding access to medical assistance in dying by stages, which you establish by age categories.

I imagine that a person's decision-making capacity can be determined as easily at age 14 as at age 15, would that be correct?

[*English*]

**Dr. Randi Zlotnik Shaul:** The staged access is not an end result that I would argue for. I absolutely agree with decisions being made based on capacity. Of course, that is not necessarily linked to age. That is the ultimate place that we're working toward. The challenge is that at this uncomfortable stage, not having had the perspective of young people informing these deliberations, how you move forward without them is a bit of a problem.

If a middle ground... I would defer to you on how you balance that when you don't have complete information, yet there's such a compelling reason to be expanding access. If the comfort level is not to be moving to the final stage based only on capacity, that was just one idea. Really, the—

• (1855)

[*Translation*]

**Mr. Luc Thériault:** I'm sorry to interrupt you. What you are saying is very interesting, but I don't have a lot of time.

[*English*]

**Dr. Randi Zlotnik Shaul:** I'm sorry. I'll try to be quicker.

[*Translation*]

**Mr. Luc Thériault:** Not a problem.

In Quebec, a person may make decisions regarding certain kinds of care at age 14. Once the age for decision-making capacity has been established and the decision is made to proceed by stages, should the first stage not simply consist in expanding access to medical assistance in dying for patients on track 1, that is, those whose death is imminent?

In terms of pediatric psychology or psychiatry, the report of the expert panel on medical assistance in dying and mental illness shows that the chronicity of the health problem had to be determined. Logically, in the case of mature minors, that would mean excluding suicidal adolescents. For other degenerative pathologies, all treatments and means of relieving the patient's pain would have

to have been exhausted. That cannot be done quickly after a diagnosis.

If access to medical assistance in dying were expanded by stages and decision-making capacity were set at between 14 and 17 years, while allowing it strictly for patients whose death is imminent, would that remove your reservation and enable us to move forward?

[*English*]

**Dr. Randi Zlotnik Shaul:** Yes. Thank you. I agree with that.

At this stage, it would be appropriate to only open up to track one patients. I agree with presentations that were made elsewhere and that are consistent with the CCA, that you could not be confident that you have an irremediable mental health challenge by 18. I'll defer to experts who weigh in that way.

I think opening up to just track one at this stage is appropriate.

[*Translation*]

**Mr. Luc Thériault:** Ms. Milne, do you want to answer too? I think there is about a minute left.

[*English*]

**Ms. Cheryl Milne:** Thank you.

I would agree with that position, that track one may be the one we're most concerned about at this stage. I think that is where we're most vulnerable in terms of a constitutional challenge on behalf of a young person. With the other track, there may be reasons for hesitation in terms of a lack of evidence and consultation with young people to understand the full impact. We could look at that at a later stage.

When we're looking at the most damaging circumstances and those serious violations of rights, we are dealing with the track one patients.

[*Translation*]

**The Joint Chair (Hon. Yonah Martin):** Thank you, Mr. Thériault.

[*English*]

Mr. MacGregor, you have five minutes.

**Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP):** Thank you very much, Madam Co-Chair.

To the witnesses, I appreciate your being here today. It's not an easy subject. We appreciate the expertise you're bringing to us.

Ms. Shaul, I'd like to start with you. You made a point in your opening statement about how there is not enough available data from mature minors. We don't know enough about their opinions on this subject, and more is needed to fill those data gaps.

I think we have an ability here, or you have an ability here before the committee, as we intend to produce a report with some substantive recommendations. I'm wondering if you have any thoughts on how the federal government could play a role in structuring that survey. What would its scope be? How would it work with other levels of government? What are the specific age ranges it needs to work out? What particular attention does it need to pay to children who are of an indigenous, racialized or disabled background?

Is there anything you can provide feedback on with regard to that, please?

• (1900)

**Dr. Randi Zlotnik Shaul:** When Mary Ellen Macdonald gave testimony earlier she talked about quite a comprehensive application that is before government for funding that is really trying to fill this gap. The pieces that are being considered, whether it's with that project or another, are from groups that have been highlighted as particularly of interest in the CCA report. That would include indigenous children, children who are in care, children with terminal illnesses, and those living with disabilities and their families as well.

We could do a deep dive in terms of what would be an excellent form of research. There may be multiple projects that could be put forward, for sure. I'm most familiar with the research institute at SickKids. There are researchers there who are wonderful, and I think there are across the country. That wouldn't be the problem. It's just the time and the funding to conduct it in a really thorough way.

**Mr. Alistair MacGregor:** Thank you for that.

Dr. Davies, I have only about two minutes left, so I'm going to load you up with a couple of questions.

First of all, do you have any thoughts on some supports that may be needed, or that we need to address, for indigenous, racialized or disabled youth? When I look at my riding out on Vancouver Island, I have a very high indigenous population. I know there are definitely some gaps in access to health care services there. Can you offer any thoughts on that?

Also, we heard that this should be brought in through a staged approach. It's probably preferable to start with track one, but this committee also has to grapple with how this issue of mature minors crosses over to our earlier discussion on mental disorders as a sole underlying medical condition. We heard from a number of people who say that even in adults it's hard to make a determination. We know with children how rapidly the brain develops. It goes through different stages.

If you could offer any expertise based on your personal experiences on that subject, that would be helpful, please.

**Dr. Dawn Davies:** Mental illness is not my specialty, but I would say that from talking to many people about this issue, there is very little appetite for that intersection of mature minors and mental illness as a sole underlying condition. To say that something is irremediable before the 18th birthday, and in addition they have capacity and we're absolutely positive about that, I think is unlikely. I would be very much in favour of going with the track one patients to start with.

On your point about how to access the voices of all the types of children and youth that we've mentioned, there are lots of child and youth advisory committees attached to every hospital. There is broad representation there, so I would encourage you to get in touch with children's hospitals. Bloorview children's hospital comes to mind for children with disabilities. I think they really are poignant when it comes to how they can inform the decisions we're talking about making.

**Mr. Alistair MacGregor:** Right. Thank you.

I'll leave it at that, Madam Co-Chair.

**The Joint Chair (Hon. Yonah Martin):** That was perfect timing for everyone. Thank you very much.

I'll turn this back over to my co-chair for questions from the senators.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Martin.

We'll begin with three-minute question rounds from our senators, beginning with Senator Mégie.

[*Translation*]

**Hon. Marie-Françoise Mégie (senator, Quebec (Rougement), ISG):** Thank you, Mr. Chair.

My question is for Dr. Davies.

I know that access to medical assistance in dying has not yet been extended to mature minors, Dr. Davies, but I would like you to base your answer to my question on your experience in palliative care.

At the point when a young patient's autonomy and vulnerability are assessed, how can we be sure that what they are saying reflects their own autonomy and that they have not, instead, been influenced by the conversations they have had with their parents, who might have stressed the fact that they are suffering and that treatment has not had the results hoped for, for example? How can an assessor get an idea of the autonomy of the young person in question?

• (1905)

[*English*]

**Dr. Dawn Davies:** I'm sorry, but I'll have to answer in English. I was doing Duolingo until you all came in.

What we imagine and what really happens when a child is dying are two different things. I think it would be so clear to anyone. By the time a child or youth actually decided to embark on this pathway, their disease would be so advanced that there would be no question. In fact, I've seen very much the opposite happen, where I've had a few patients who could have opted for MAID—they were past their 18th birthday—and have not. I have actually had one 19-year-old die by suicide when his disease became too advanced, but not through the channels we're talking about.

The assessment would not be difficult, and I think parents by and large eventually come to see what is happening to their child and become supportive, even if it takes some time.



In the case of younger children, the parents can see what's happening and wish they could exert some decisional capacity over the situation as they would for many other health decisions they make on the part of their child, but I don't think the evaluation would be difficult.

[Translation]

**Hon. Marie-Françoise Mégie:** Based on your clientele, do you think that some minors who are receiving palliative care would request medical assistance in dying if they had the option?

[English]

**Dr. Dawn Davies:** No, and I think when we look to other countries, we know the numbers are very low.

When we did the Council of Canadian Academies review for the Netherlands, for example, I think there were 10 to 13 children. It's very low, very infrequent.

In my clinical experience, the ability of a youth to say, "I think I'm dying" often comes on the day they die or the day before they die. Most children and youth want to live. They want desperately to live, and I think that's why going through a very formal channel like this is going to be done very infrequently, because by the time they come to that realization, it will probably be too late.

[Translation]

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Mégie.

[English]

Senator Kutcher, go ahead for three minutes.

**Hon. Stanley Kutcher (Senator, Nova Scotia, ISG):** Thank you very much, Chair.

Thank you so much to our witnesses. I think your thoughtful ideas here about addressing track one have been very helpful to the committee, so I thank you for that.

Currently the Canadian Association of MAID Assessors and Providers is developing a training program, which should soon be finished, on MAID assessment and provision. It will be certified by the Royal College, The College of Family Physicians of Canada and the Canadian Nurses Association.

Are you aware of that program and whether it addresses the issue of mature minors in its totality?

If you're not aware, or if it doesn't, do you think something like this should be developed for mature minors, perhaps under the auspices of the Royal College as well as the Canadian Paediatric Society, something so that we would have comfort that MAID assessors and MAID providers dealing with mature minors really are meeting a particular standard of professional competency?

That is for any one of the witnesses.

**The Joint Chair (Hon. Marc Garneau):** Perhaps you could you direct it, because they'll all hesitate.

**Hon. Stanley Kutcher:** This is for Dr. Davies, Dr. Zlotnik Shaul and Cheryl Milne, please.

**Dr. Dawn Davies:** Something we talked a lot about at the Council of Canadian Academies is that I don't think we would imagine panels and putting these children and youth through an extra lens of security for us. I think it needs to be embedded in the child's health care team that everybody feels certain that the child has the capacity to make that decision.

If there was some extra level of sober second thought for this decision, I think it would have to be within the child's team and not some external mechanism. I'm not aware of the MAID providers' training program. There may be nuances that would help them in dealing with youth and mature minors, but I don't think it would be that much different from the work they do every day.

● (1910)

**The Joint Chair (Hon. Marc Garneau):** Ms. Milne.

**Ms. Cheryl Milne:** The standard we have used for medical decision-making for youth and for mature minors—even though that's not really a legal term, as there isn't a real definition of that—is one that applies both for adults and for children.

Where there's some nuance is around the voluntary aspect of decision-making, because children and young people tend to make those with their families supporting them. Differentiating between a decision that is the autonomous decision of a young person and one they're making with their family is where we wouldn't want to see that decision being discounted because they're being supported by their family in making that decision.

That's the one tricky area, I think, but mostly it's the same standard of appreciating and understanding what is being proposed, the ability to make that voluntary choice, and understanding the gravity of the decision.

What we know from the case law around withdrawal of treatment and refusal of treatment is that when the gravity of the decision is such that the young person is refusing life-sustaining treatment, for example, a significant amount of scrutiny from the medical team is placed on that decision. That is just the standard practice, so I don't think we need to make it more difficult for the young person to make that decision legally.

**The Joint Chair (Hon. Marc Garneau):** Thank you.

Although the time has run out, Ms. Zlotnik Shaul, would you like to quickly comment?

**Dr. Randi Zlotnik Shaul:** Sure.

If I understood correctly, you were asking about a training process. In terms of the clinicians I've spoken to, there is an appetite for some clarity of the associated expectations, should it be expanded to mature minors. Whether or not this clarity of expectations comes from a regulator or a framework that's endorsed by the Royal College, that clarity is something that I think there is an appetite for. It's not an extra layer of steps to take, but for a clarity of expectations that will likely just be, as Cheryl was saying, similar to what currently happens for other decisions.

Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you.

[Translation]

Senator Dalphond, you have the floor for three minutes.

[English]

**Hon. Pierre Dalphond (Senator, Quebec, PSG):** Once more, thank you very much to the witnesses. It's very useful, and I share the view that precautions are necessary.

My question is for you, Dr. Davies. You say that they realize they're going to die quite late in the stage. The battle is over. They lose hope, and they'll die shortly after. In fact, will they have access, in practice, to the MAID process, or will they end up being in palliative sedation because they reach a point where they are suffering so much? Who's making that decision? Are the parents deciding when the child, even if he's 17, is in such intense pain?

**Dr. Dawn Davies:** I'd have to say that most of the children and youth I have cared for do not need palliative sedation at the end of life—that's rare. That's why I think the numbers will be low of the youth who actually want to embark on a process like this. Some may, because of that need for autonomy and to have things go the way they want them to go, but I think many youth will not be able to accept, even to themselves, that they are dying until it's too late.

That's one of the main reasons the numbers will be low. I think the number of adults has borne that out. The number of people in their twenties is very low compared to the number of older patients.

**Hon. Pierre Dalphond:** The team who will accompany the family, because I guess it's a family experience and not the most fortunate one, are they raising the issue with the patient and the family, or do you wait for when the request comes?

**Dr. Dawn Davies:** I have had very few conversations with youth about this. There are very few young people who have wanted to talk about hastening their death. The people I've spoken to are parents of not capable children who wonder why their child must continue to suffer. That's just my lived experience as a clinician.

• (1915)

**Hon. Pierre Dalphond:** Thank you.

[Translation]

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Dalphond.

[English]

We'll go to Senator Wallin for three minutes.

**Hon. Pamela Wallin (Senator, Saskatchewan, CSG):** Thank you very much.

I just want to say thank you. I'm not sure who said it, but I think the most powerful statement today is that delay is not a neutral decision. That applies to the entire discussion we've been having, for years now, in this country.

What I hear in this conversation is that we're trying to deal with our own concerns. As legislators and as medical professionals, we want to make sure we're doing the right thing when this is really about mature minors, the child and the young person's capacity, and it's their call.

My question is about this process of hearing their voices. When the numbers are so small in the first place and we're talking about funding projects and going out and giving voice, I am just afraid this is another example of pushing this down the road when, in fact, delay is not neutral. We have some kind of agreement here on track 1.

I'll start with you, Dr. Davies. Does it concern you that we will just push this further down the road?

**Dr. Dawn Davies:** Yes. If you limited it to the youth who were imminently dying, we could learn from their experience, and that might inform the other groups of youth going forward. It's true that delay is not neutral, but on the other hand, this is a new sort of experiment for humanity, if you will. We still need to be careful and go slowly. It's just like research. There are baby steps to inform the next stage. To me that makes sense.

**Hon. Pamela Wallin:** Do we have this? I don't know if Cheryl Milne or Randi, if I could just call you that... I think you mentioned this, Dr. Davies, as well. This data, does this information exist at children's hospitals?

Obviously, care teams have spoken to children, to families and to legal advisers. Does that not exist anywhere now? Is there not commentary that we can mine?

Cheryl, do you want to go ahead with that?

**Ms. Cheryl Milne:** I'm not sure if I'm the best person to answer that.

What happened with the expert panel is that there were some interviews done with some young people who were part of Bloorview and another sort of treatment centre. Mostly, when you talk to young people, they want to be respected and listened to. They want to be treated equally, particularly if they are competent to make decisions. We start from that as a premise.

The other information we need is about those other groups that we may be expanding MAID to include that we don't know enough about—the young people's experience.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator.

We'll now go to Senator Martin for three minutes.

**The Joint Chair (Hon. Yonah Martin):** Thank you to our witnesses for your insights, which are very important for this really serious discussion about mature minors.

As a parent, I can't even imagine being in a position to have to consider such a decision, even with a very mature child. A parent should not have to bury their child. It's such a heavy topic for us. Thank you for your insights.

My questions are for Dr. Zlotnik Shaul.

The committee heard from a number of witnesses who were concerned about how social factors such as poverty, stigma, abuse and the lack of access to care might affect minors' decision-making about MAID.

In your view, how do social factors affect a minor's decisional capacity and/or the decision-making process?

**Dr. Randi Zlotnik Shaul:** That's a rich question, for sure.

I might defer to Dr. Davies in terms of the capacity assessment, but I think having the capacity piece not tied exclusively to an age is giving recognition to fact that the lived experience of an individual informs their ability to understand and appreciate the question before them. In terms of social context and in terms of experience in living with an illness, all these pieces will inform and add to the maturity they may have in regard to their current context, as compared to somebody who may just be newly in a position of living with an illness.

One's social context and one's lived experience—all of those pieces—are what add to one's maturity and capacity to make a particular decision.

• (1920)

**The Joint Chair (Hon. Yonah Martin):** Do social factors have a greater or different influence on minors as compared to adults?

**Dr. Randi Zlotnik Shaul:** I'm not sure in terms of greater or less, but definitely significant.... I mean, again, if we're thinking in terms of moving forward in a multipronged way, it is really imperative that thinking about doing right by young people includes attending to social determinants of health and includes being cognizant of inequity related to palliative care.

Maybe that would be part of the conversation going forward if there is an expansion of MAID: that it go forward with attention to other places where we need to do better and a plan to do so.

**The Joint Chair (Hon. Yonah Martin):** My last quick question is this: Should a minor be disqualified from MAID due to their social circumstances, in some cases?

**Dr. Randi Zlotnik Shaul:** I don't think so. I mean, you would still go through the process of understanding and appreciating. In a sense, that would be somebody who is living with inequity then having a further inequity in terms of not being able to access assistance while being in a state of irremediable suffering.

I wouldn't say that should be disqualifying. If anything, that's an impetus on us to have to try to do better to address inequity that's existing in terms of social circumstances. This isn't a quick fix for sure, but this is a highlight of where we have to do better.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Martin, and thank you to our witnesses. This brings our panel to a close.

I'd like to thank Dr. Davies for being here with us tonight, as well as Ms. Milne and Dr. Zlotnik Shaul.

Thank you for providing your opening remarks and for answering our difficult questions, and for your expertise on this matter. We very much appreciate it.

With that, we will suspend momentarily to prepare for the second panel.

Thank you.

• (1920)

(Pause)

• (1925)

**The Joint Chair (Hon. Marc Garneau):** I welcome the second panel.

We have the issue of a vote at 8:30, with bells going off at 8:00. Is there unanimous consent for us to go for 20 minutes after the bells?

**Some hon. members:** Agreed.

**The Joint Chair (Hon. Marc Garneau):** Thank you. Very well.

We'll have to be very disciplined on the time.

With that, I'd like to make a few comments for the benefit of our new witnesses.

Before speaking, please wait until I recognize you by name.

I will remind you that all comments should be addressed through one of the joint chairs.

When speaking, please speak slowly and clearly for the benefit of the interpreters.

You have the choice of interpretation in this video conference. At the bottom of your screen there is a choice of either floor, English or French audio. There will certainly be questions in English and in French.

When you are not speaking, please keep your microphone on mute.

With that, I would like to welcome our witnesses for panel number two, who are here to discuss mature minors.

They are all appearing as individuals.

We have Caroline Marcoux.

[*Translation*]

We also have Professor Roderick McCormick with us.

[*English*]

We have Timothy Ehmann, who is a medical doctor and a child and adolescent psychiatrist.

All three are appearing by video conference.

Thank you to all of you for joining us.

We'll begin with your opening remarks, which should be limited to five minutes.

I'll ask Ms. Marcoux to start off, followed by Dr. McCormick and then Dr. Ehmann.

Ms. Marcoux, you have five minutes. Please go ahead.

[*Translation*]

**Mrs. Caroline Marcoux (As an Individual):** Thank you, Mr. Chair.

Good evening, everyone.

My name is Caroline Marcoux. I am the mother of the gorgeous Charles, whom I have with me, right here.

On July 30, 2019, Charles received a diagnosis of osteosarcoma, a cancer of the bones, in his right femur. At that time, Charles was 15 years and nine months old.

Over the next year, he went through a whole series of chemotherapy treatments and had major surgery on his leg to remove the mass. Charles was always cheerful, optimistic and smiling, as you can see. He was an exemplary and very resilient patient during his illness.

A few months after the treatments ended, he was told the cancer had returned, in both his lungs. He had surgery on each of the two lungs to remove the metastases, but in spite of this, the disease came again immediately after, not just in both his lungs, but also in his knee. Once the cancer had recurred twice, we know that the disease was irremediable and nothing more could be done to halt it. That was in January 2021.

As always, Charles accepted what was happening to him. Psychologically, he still felt well, but his physical health started to decline, bit by bit. He had less and less energy, less and less appetite, and more and more pain. In fact, from January onward, he was having about one good day out of two.

Still, he proudly completed an important milestone in the life of a 17-year-old young man: he got his driver's licence. At that point he was missing one lung, because his left lung was full of liquid and there was nothing more to be done for it. His driver's licence meant that he was able to enjoy his autonomy about three or four times in the week that followed. That was all. After that, he was no longer in shape to leave the basement of the house.

Starting then, and even a little earlier, all the medical care, emergency services and drug dosages were handled by the palliative care team. The team did its best, within the limits of the options available to it, but was never able to completely relieve the pain. That is without mentioning the side effects: Charles was hot all the time and slept very badly. The drugs were not doing the job. He took Dilaudid, morphine, fentanyl, methadone—everything he could get to relieve the pain. The number of drugs he was taking kept going up, because the pain and the symptoms were constantly increasing. His lungs hurt, his shoulders hurt, and he had a distressing loose cough. His condition was not improving.

At the beginning of July, shortly after he got his driver's licence, he was barely getting out of the hospital bed that was brought to the basement for him anymore. Most of all, he was fed up: fed up with doing nothing, fed up with watching television, fed up with being sick and fed up with not having any quality of life. That was his situation. He started worrying about death. He wondered when death was going to come, whether he would be alone when it did and how it would happen. He was calm and collected by nature, but he start-

ed having anxiety attacks, anxiety and panic attacks, which showed how completely powerless and at the end of the rope he was.

In about mid-July he started talking about medical assistance in dying. He talked to me about it and he talked to the social worker and the doctor. He could not go on suffering and waiting for death any longer. We knew that the end was imminent; that was not the issue. He would have liked to have the choice and control over the time of his death. That would probably have reassured him. What he said was that he would have liked to have control over the disease, in at least that respect, because he had not had any control for the previous two years. He had never talked about death before that point. He had always been positive. When he made that request, he was already in the terminal phase. We knew that death was imminent, but he had to wait, because he was then 17 years and nine months old.

● (1930)

It is inhumane for a mother to hear her child say: "Mom, do something, I can't take any more." I accompanied him in it, in his suffering, to the end. I would have liked to do as he wished and do everything I could to calm his anxiety and his pain. All the doctors could do, again, was increase the medication. He was having trouble talking, because he was very medicated. He wasn't eating. At least, he was able to express his needs and tell us what he wanted.

The only possible solution, at that point, was palliative sedation. One day, he asked for it. He was completely fed up and just wanted to sleep and not be aware of his condition. So he went into the hospital pediatric ward, because that is what he wanted. He was put into a state of induced sleep. We watched over him for 24 long hours, and his sleep did not seem peaceful. Again, it was as if the drugs were not enough to calm him, any more than they had been enough to relieve his pain before. He did not seem to be comfortable. As a mother, I had to see him in that state, not being able to understand his needs, waiting for him to be completely unconscious. It took 24 long hours.

He died on July 30, 2021, exactly two years to the day after his diagnosis. So he was 17 years and nine months old.

I lost my boy, but I hold onto the two promises I made him. First, the promise to go on the trip of his dreams to England. And second, at the point when he asked for medical assistance in dying, I promised him that I was going to do everything I could to campaign, or at least to speak up as I am doing tonight, so that it would become accessible to young people like him would like to have it.

Charles was a very mature young teenager, even before his illness. He lived with his disease for the last two years of his life, with a serenity that gives me the strength to get through this period, through his loss. I cared for him until the end, and I would have done it as long as he needed. I didn't want to lose my boy, certainly, but I could not see him suffer any longer, nor could he suffer any longer. He had truly reached his physical and psychological limits. I would have cared for him to the end, but I hoped not to have to care for him when he had reached a stage when he had lost his dignity. I hoped not to have to change his diapers and see him grow thinner until he was a walking corpse. I would have gone there, but I hoped that it would not be the case. Fortunately, when he died, he still had his gorgeous chubby cheeks, so we were spared that, but he was truly at the end of his rope.

I know that the decision to expand access to medical assistance in dying to mature minors is not to be taken lightly, nor did Charles, from the height of his 17 years, at the end of his life, take it lightly. It might not have hastened his death by much, since he was already at the end of life. The date he would have set might have been a few days after July 30. But he was ready and he deserved that choice. It would have been his decision, in the end. It would have been he who chose the time to leave and the people who would be with him. That is the only choice, or at least the last choice he would have been able to make in his life.

• (1935)

**The Joint Chair (Hon. Marc Garneau):** Thank you, Ms. Marcoux, for that very personal and very moving testimony about your son Charles.

[English]

We'll now go to our second witness, Dr. Roderick McCormick.

Dr. McCormick, you have five minutes.

**Dr. Roderick McCormick (Professor, As an Individual):** *Shé:kon.*

My name is Dr. Rod McCormick. I'm Mohawk, or *Kanien'kehá:ka*. I'm also a professor and research chair in indigenous health at Thompson Rivers University. I live on my partner's first nations reserve of Tk'emlúps te Secwépemc, in Kamloops, B.C., and I'm the director of the indigenous research centre called All My Relations.

I'd like to thank the committee for the invitation to provide input once again on Bill C-7. Previously, I testified on the implications of Bill C-7 for those suffering from mental illness. I'd like to extend those views as they pertain to MAID for mature minors.

The expansion of MAID is occurring at too rapid a pace, in my opinion. I've learned through painful experience that when you're on a slippery incline or hill, or in this case a slippery slope, the best way to avoid falling is to take small, careful steps.

As I'm an indigenous health professor and research chair who has also had approximately 35 years of experience as a mental health service provider for indigenous people, my testimony will be from an indigenous mental health perspective.

I should start by saying that I have grave concerns over the extension of MAID for minors, and I use the term "grave" in a purposeful manner. As my partner and kids are members of Tk'emlúps te Secwépemc and I live in their community, I experienced first-hand the impact of the announcement of the 215 children's graves on the grounds of the residential school. I can clearly see the residential school from the windows of my house and can make out a glimpse of the fields in which the 215 children were buried in shallow graves.

This attempt to conceal the bodies is, in a way, symbolic of the numerous historical attempts by Canada to deal with what Duncan Campbell Scott referred to as the need to "get rid of the Indian problem". Those attempts, as many of you probably know, consisted of forced starvation, forced sterilization, forced relocation to reserves with unsafe, unhealthy and crowded housing, the introduction of liquor, smallpox blankets, forced residential schooling, experimentation with malnutrition in residential schools, ignoring the contagion of tuberculosis in the residential schools, the ongoing child welfare seizure of children and the excessive imprisonment of indigenous peoples in the penal system. The list goes on.

What I'm saying is that because of the multiple ways Canada has utilized to eliminate indigenous peoples and culture, we are over-represented at every stage of the health care system, including that of premature deaths. This may all seem overly dramatic to you, but do we really need yet another path to death?

My cynicism is partially based on decades of working with indigenous youth to help them attain and maintain a good and healthy life. As I mentioned in my previous testimony, I've worked with many indigenous youth in emotional pain who were able to recover from being suicidal. The common reflection they had upon recovery was one of relief that they did not choose a permanent solution to what proved to be a temporary problem. Getting the proper and timely help is key to survival.

There are many barriers to obtaining that help. Among them are a lack of accurate diagnoses and corresponding treatments, a racist health care system, a mistrust of a health care system that doesn't always have our best interests in mind, jurisdictional ambiguity and the abdication of responsibility by various governments. The big factor is the remoteness of our communities.

Living on reserve and/or in a remote location often means that health services are provided by nurses or nurse practitioners, who are often overworked and ill prepared to provide the range of services that are required. This is especially the case in the near total absence of palliative care services for indigenous children and youth.

In preparing this statement, I scoured the Internet looking for evidence showing that mental illness can be predicted to be irremediable, and I couldn't find any. Shouldn't public policy as important as this be informed by evidence?

Some argue that we'll be discriminating against minors and those with mental anguish if they are not allowed access to MAID. However, without evidence, are we not also discriminating against those very groups in another way?

Currently, I believe the law provides the option for the minor to self-assess as to whether various methods of treatment are appropriate for them, and to refuse such treatment they deem inappropriate. From my clinical experience, most youth are not aware of the diverse treatment options they have, nor do they have an accurate understanding of them. Granted, for indigenous youth, those options might not even be available to them in their communities, but shouldn't equal health care in Canada be available to all Canadians?

• (1940)

Can teenagers whose brains are still developing make such important decisions?

Although I obviously cannot speak for all indigenous peoples, the pattern I am seeing with the introduction and expansion of this legislation is that of an abdication of responsibility by the Government of Canada and, by extension, by the citizens of Canada.

Instead of making every effort to provide the range of mental health services needed by indigenous youth to overcome their pain, we are instead imposing upon them the burden of deciding whether they should choose a government-sanctioned, permanent solution to what could easily be a temporary problem. That is where mainstream Canadian cultural values fail us all. The emphasis on individual rights and individual freedom is not balanced with the need for collective responsibility.

In closing, I would like to read you a statement by the existential psychiatrist, Dr. Viktor Frankl.

Freedom, however, is not the last word. Freedom is only part of the story and half of the truth. Freedom is but the negative aspect of the whole phenomenon whose positive aspect is responsibility. In fact, freedom is in danger of degenerating into mere arbitrariness unless it is lived in terms of responsibility.

I urge this committee to advocate for the Government of Canada and the provinces to accept their collective responsibility to not expand MAID to minors but to instead improve the mental health services available to indigenous youth and all the youth of Canada.

*Nia:wen.* Thank you.

• (1945)

**The Joint Chair (Hon. Marc Garneau):** Thank you, Dr. McCormick.

We'll now go to Dr. Ehmann.

Dr. Ehmann, you have five minutes.

**Dr. Timothy Ehmann (Medical Doctor, Child and Adolescent Psychiatrist, As an Individual):** Thank you for the invitation to stand before this committee.

My name is Dr. Timothy Ehmann, and I have been practising child and adolescent psychiatry for 10 years in a variety of in-patient, outpatient, academic and community settings.

I would like to begin my testimony by stating categorically that to extend the current MAID regime to minors—mature or otherwise—is negligent and irresponsible.

This debate began shortly after I began practice and has been like a dark cloud looming over my early career. I have followed as the Government of Canada has forged ahead despite many warnings to

desist. I am adding my voice to say that it would be wise for the government to proceed no further down this dark path.

The proposition that death is a legitimate treatment for any form of suffering is false.

The proposition that the physician community can reliably assess the competence and capacity of minors to consent to death is false. It is not supported by any available research on the subject. Any physician who peddles this message is doing little more than saying, "Trust me; I'm a doctor."

There does not exist any standardized, reliable and valid assessment for determining the capacity and competence of minors. Research has demonstrated that unaided competence judgments, even from seasoned and otherwise skilled physicians, are unreliable. In a routine medical practice, children are oftentimes incompletely informed, and the communication between an adult physician and child is oftentimes flawed.

There are many systemic influences on a child's decision-making. No decision is made free from influence. This raises the important question of how to evaluate precisely how free the child is in any decision. One new systemic influence just might be the cultural shift that the Government of Canada is propagating, which is moving our society increasingly towards a culture of despair.

The government messaging that it will offer death as a solution to life's suffering is suicide inducement. We are well aware of the phenomenon of suicide clustering in youth, such as on reserves, and that messages of despair increase suicide rates.

It is a difficult time to be a child in Canada.

MAID is not an evidence-based medical practice. As such, compelling physicians to adopt this practice through law sullies and undermines the integrity of the medical profession. Canadian physicians have been trained to practice modern, evidence-based medicine directed by scientific fact, not postmodern, ideologically-based medicine directed by political authorities.

MAID is an experimental practice without pre-existing safety data, adverse outcomes reporting, or adequate safeguards and accountability. The Government of Canada needs to hold itself to the same level of accountability and standard as it would hold any pharmaceutical company before a new drug or treatment is introduced to the Canadian population. We do not subject children to high-risk experiments.

Minors are a categorically vulnerable population. Postmodern philosophies that postulate that to exclude vulnerable populations from their right to death is to discriminate against them are shallow and dangerous. Legislation that is undergirded by these philosophies is a risk to our children.

The Canadian government and its representatives are conducting themselves paternalistically with regard to the MAID regime.

Organizations representing disadvantaged and vulnerable groups within our society that have presented evidence to this committee have been disregarded. These representative groups have asked for either safeguards or exclusion from eligibility for MAID for their communities and been denied such. The Government of Canada has effectively communicated to these groups that the government knows better what is in their interests than these vulnerable populations themselves do.

In modern society, with modern medicine and scientific advances, the need to kill a child does not exist. Why then the Canadian government's headlong rush to open up the MAID regime to minors?

Thank you.

• (1950)

**The Joint Chair (Hon. Marc Garneau):** Thank you, Dr. Ehmann.

We'll now go to questions. I'll pass it to my co-chair, Senator Martin.

**The Joint Chair (Hon. Yonah Martin):** Thank you.

I'm just wondering if MPs are all right if we do four-minute rounds. Is that okay?

[*Translation*]

Mr. Thériault, do you agree?

**Mr. Luc Thériault:** Yes.

**The Joint Chair (Hon. Yonah Martin):** Thank you.

[*English*]

We'll begin with Mr. Cooper for four minutes.

Are you sharing—

**Mr. Michael Cooper (St. Albert—Edmonton, CPC):** Thank you, Madam Chair. I'm going to share one minute of my time with Madame Vien.

Dr. Ehmann, some witnesses who have come before the committee have noted that mature minors make complex and significant medical decisions, and therefore it follows that MAID ought to be expanded to mature minors. What do you say?

**Dr. Timothy Ehmann:** What complex decisions are you referencing?

**Mr. Michael Cooper:** An example would be the decision to end life-sustaining treatment.

**Dr. Timothy Ehmann:** What is a minor's capacity to end a life-sustaining treatment? I don't know the details as well as probably some of the lawyers of the case, but I believe it was recently ruled on in *A.C. v. Manitoba*. I know that it's a complex assessment. It takes into account the emotional, intellectual and psychological state and the maturity of the child. The context occurs not just with the child alone but also in the broader context of the family.

Of course, in our culture we look at children as individuals. As adult assessors, we're trying to determine at what point they have the capacity or the intellectual ability that we possess to make our decisions. One thing we forget about is that there's a theory that children actually are one part of a larger organism, that larger organism being the family. It's a very complex decision.

**Mr. Michael Cooper:** How would you distinguish that for MAID, for example? It's a broad question, but the point being made is that if mature minors can make some of these life-altering medical decisions, then why shouldn't they also have the option of MAID?

**Dr. Timothy Ehmann:** Right: Why shouldn't they have the option that we're giving adults presently? Refusing a life-sustaining treatment and asking for a treatment where the objective is death are fundamentally and categorically two different things. You can't compare the two.

**The Joint Chair (Hon. Yonah Martin):** You have 40 seconds, Mr. Cooper.

**Mr. Michael Cooper:** Okay.

You spoke about research with respect to competence judgments and the unreliability of such judgments. Can you expand on that research?

**Dr. Timothy Ehmann:** Yes. As it pertains specifically to the child and adolescent, there are many articles in the literature discussing this issue, but there have actually been no systematic studies. As recently as 2012 or 2014, assessors were starting to look at how we objectively assess the capacity of minors to consent to be research participants in medical studies. As recently as then, they were stating that there is no objective assessment, no standard of assessment, for determining that this child has capacity and this child does not have capacity.

There was a review in 2020—

**The Joint Chair (Hon. Yonah Martin):** Thank you, Dr. Ehmann. I have to stop you there. I'm sorry.

Madame Vien, you have one minute.

[*Translation*]

**Mrs. Dominique Vien (Bellechasse—Les Etchemins—Lévis, CPC):** Thank you, Madam Chair.

Hello, Ms. Marcoux.

I will get straight to the point: would you say that Charles had the capacity to decide?

**Mrs. Caroline Marcoux:** Absolutely.

**Mrs. Dominique Vien:** Tell me what makes you believe that Charles had the capacity to make that decision.

**Mrs. Caroline Marcoux:** Charles was always a determined young man who had his own ideas and was always mature. He was a positive leader. By facing the ordeal of his disease, he gained even more maturity. His resilience made him our pillar. He was completely lucid and aware of his situation. He knew that death was imminent and there was nothing left to do. For two years, he made the medical decisions about himself of his own free will, in his own mature way. That decision was also his own. Neither I nor anyone else spoke to him about medical assistance in dying. The question came from him, because he couldn't take any more.

• (1955)

**Mrs. Dominique Vien:** Thank you.

**The Joint Chair (Hon. Yonah Martin):** Thank you, Ms. Vien.

[English]

Next we will go to Mr. Anandasangaree for four minutes.

**Mr. Gary Anandasangaree (Scarborough—Rouge Park, Lib.):** I would like to thank the panel.

I want to particularly thank you, Madame Marcoux. Thank you for bringing a real-life perspective to this discussion.

You have heard from both Mr. McCormick and Mr. Ehmann. I'm wondering if you could take a couple of minutes to walk us through what you went through, your perspective of Charles's ability to make a decision and what challenges you faced as a family in accessing MAID for a mature minor. I'm also wondering if you could speak to some of the issues brought forward by Mr. Ehmann with respect to MAID being something that should not be available to minors overall.

[Translation]

**Mrs. Caroline Marcoux:** During the two years of his illness, Charles chose the type of operation he would have on his leg, he chose to stop the treatments at the point when there was no further point in taking them, he tried things—all the medical decisions were made by him, with the support of the medical team, after discussing them with the doctors. Yes, it was a family decision, and yes, we talked about it, and the family does have to be consulted in all of that. However, at the age of 17, he had the capacity to make his own decision.

From spending time with sick children for two years, I saw that illness often brought them additional maturity, a kind of wisdom. There may not be scientific proof of that, but it is based on experience. For some, maturity comes with illness.

At the end, it was Charles' decision. He did not make the decision when he was diagnosed. He did not give up when he was diagnosed or during the treatments. He made that decision right at the end, when he couldn't suffer any longer and he had lost his autonomy and his dignity. If he had been in exactly the same situation but had been three months older, and thus an adult, he could have requested medical assistance in dying. And yet Charles was more mature than many adults who have the right to make that decision.

[English]

**Mr. Gary Anandasangaree:** Thank you, Madame Marcoux, for sharing this with us again.

As you advocate, because I know this was one of the commitments you made to Charles, for the availability of MAID for mature minors, I want to get a sense from you of what types of obstacles or challenges you've faced in ensuring that MAID is available for mature minors.

**The Joint Chair (Hon. Yonah Martin):** Please be very brief.

[Translation]

**Mrs. Caroline Marcoux:** In fact, I have not taken a lot of actions to date. Today is the first major thing I am doing. What I have been doing for a year and a half is mainly raising awareness among my family and friends. When I can talk about it publicly, I do. I focus on raising awareness. I haven't faced any obstacles so far in telling Charles' story. In any event, the people I have talked to about it have seen the need for expanding access to medical assistance in dying.

**The Joint Chair (Hon. Yonah Martin):** Thank you.

[English]

Next we have Monsieur Thériault for four minutes.

[Translation]

**Mr. Luc Thériault:** Thank you, Madam Chair.

Hello, Ms. Marcoux. Thank you for accepting our invitation.

• (2000)

**Mrs. Caroline Marcoux:** It really am pleased to do it. It is always a pleasure to talk about Charles.

**Mr. Luc Thériault:** You said that Charles had two wishes. I want to reassure you: tonight, you are doing a masterful job of fulfilling one of his wishes by talking to us like this and by being such a strong voice to convey his wishes.

You told us that Charles deserved the choice of medical assistance in dying. If he had had that choice, in the situation he was in, do you believe it would have lessened his anxiety and pain? If so, why?

**Mrs. Caroline Marcoux:** I think it would have. He truly was just waiting in fear: he was waiting for death and he was afraid of not knowing when it was going to happen. Yes, the drugs managed to calm his anxiety for a bit. Then he couldn't take it anymore. He requested palliative sedation because it was the last solution remaining to him. He simply wanted to sleep and not be suffering anymore.

It would have given him peace, to be able to choose, to have control over the final moment and be sure I was going to be with him. That is actually something that worried him a lot: I had to be with him constantly, night and day, because he was afraid of finding himself alone and dying all alone. If he had had the choice, my feeling is that it would have reassured him. Being able to decide simply where, when and with whom he was going to die would have been reassuring for him.

**Mr. Luc Thériault:** Of course, it was his choice to request palliative sedation, but was that his number one choice? How did he look at palliative sedation? Did he come to that decision easily?



**Mrs. Caroline Marcoux:** It was plan B. Once he knew he could not receive medical assistance in dying, he knew that palliative sedation was the only remaining option. He waited a bit, because there was a new drug that had managed to calm his anxiety. He waited a few days, but in the end he requested it. But it really was his plan B. Palliative sedation was a solution because he had no other choice, but it was not option A for him.

**Mr. Luc Thériault:** Did that decision make him as calm as he would have been if he had been given medical assistance in dying? Did that solution shock him?

**Mrs. Caroline Marcoux:** He was shocked from the moment when he knew he was not entitled to medical assistance in dying to the moment when he decided to request palliative sedation. Between those two moments, he was angry and he was very anxious. He was shocked that he did not have access to it.

Plan B, palliative sedation, calmed that anxiety. Once he made the decision to request palliative sedation—to be put to sleep—it worked for him. It was the state that it left him in for 24 hours that was difficult. In fact, he was already at the end of life. He might have died the same day anyway, even if he had not received palliative sedation. He was completely at the end of his rope.

So yes, he felt angry for a while.

**The Joint Chair (Hon. Yonah Martin):** Thank you.

[*English*]

Next we have Mr. MacGregor for four minutes.

**Mr. Alistair MacGregor:** Thank you, Madam Joint Chair, and thank you to our witnesses for being here today.

Madam Marcoux in particular, thank you for having the courage to share a very personal story with us. We certainly offer our sincere condolences to you for what you and Charles went through.

We have had a number of witnesses on this subject who have discussed when capacity forms. Your son Charles was almost an adult. He was almost legally an adult at age 17. I'm just wondering, had this disease struck earlier, at a younger age.... How do you think you and Charles would have approached this question if, say, he'd been 12, 13 or 14? I'm just wondering, because I think that's an important question for our committee to consider, especially when we're dealing with pretty young ages and these terrible diseases strike.

• (2005)

[*Translation*]

**Mrs. Caroline Marcoux:** That is still hypothetical. I can't know how he would have experienced it at age 12, but Charles was always mature, regardless of his age. He was not a scatterbrain. He was just a normal teenager. He was very calm and very collected. In his case, he probably would have been just as mature at the age of 12 or 13.

As I said, the sick children I have seen, both toddlers and older kids, were calm about being sick. I talk a lot with other parents who have also lost their child, and it was their child who helped them. It is our children who help us get through the illness and then get through the grief, because they themselves accept it, quite simply.

They have the maturity, the resilience, that enables them to accept the illness, to live with the illness, to do what has to be done to overcome it or to accept death when they can't overcome the illness.

Would Charles have made the same decision? Would he have been at the end of his rope at age 12, too? Probably yes, but we will never know. The fact remains that the situation would have been the same and there would have been the disease and all the same problems for two years.

[*English*]

**Mr. Alistair MacGregor:** Thank you for that.

For my last couple of minutes, I just want to turn to Dr. Ehmann.

Dr. Ehmann, I listened to your opening statement and I understand that you have a very strong position on this matter, but you also had the benefit of listening to a very personal story. I'm just wondering, sir: Is your position on this absolute? If you're dealing with a minor who has an incurable disease like cancer, who's obviously living through such pain and suffering, are you as a doctor of the position that the only option available to them is to go through palliative sedation? To your mind is there ever an exception to this, or is your position absolute on this, that it should be denied until age 18 in all cases, no matter the circumstances?

**Dr. Timothy Ehmann:** I'm a child and adolescent psychiatrist. Let me share a story with you.

I had a 17-year-old adolescent whom I cared for back in 2018. Her mother had died when she was seven. For the next three years she was sexually assaulted repeatedly by a family member. Between the ages of 10 and 12 she immigrated to Canada. In Canada, after a handful of years, at the age of 15 she was kicked out by her father. She lived independently, went to school full-time, and worked in fast food for pretty much 40 hours a week.

I met her in the emergency department. She was suicidal. I admitted her to hospital. I was the first person that she shared the sexual abuse with. After sharing that with me, she fell apart. She had full-blown PTSD and depression. I sat with that child, day in and day out, with her sobbing, asking, "Dr. Ehmann, let me die. Let me go home. I want to die." It was the worst psychological suffering I've ever witnessed. It affected me profoundly, personally. She spent six months on our in-patient unit, in and out.

I can tell you, I wondered about that question of what is the right thing to do. At the end of the day, however, when they are faced with their patients who are suffering from a medical condition, a mental health condition or from life circumstances, the physician's rule is always to protect and preserve life—and I am committed to that.

I don't know how she's doing now. I know that she made it through those hospitalizations and recovered, in part because of the service that we provided in the hospital. Because she was there for six months, my colleagues were all involved with it as well.

**The Joint Chair (Hon. Yonah Martin):** Thank you, Dr. Ehmann.

At this time, I will return this back to my joint chair.

**The Joint Chair (Hon. Marc Garneau):** Thank you.

As you know, members, we have to break in 13 minutes because of a vote. To allow each of the senators a chance to speak, I'm afraid I'm going to have to limit them to two minutes per senator.

[Translation]

Ms. Mégie, you have the floor for two minutes.

**Hon. Marie-Françoise Mégie:** Thank you, Mr. Chair.

I would like to thank the witnesses. Thank you to Ms. Marcoux for talking to us about something so personal. My question now is for Dr. Ehmann. If Professor McCormick has time, he can answer too.

Dr. Ehmann, everyone understands your position. In your opinion, should the government establish a legislative framework for this type of request or wait for a minor and their family to take the issue to court?

Is there a good way for the federal government to address this issue?

• (2010)

[English]

**Dr. Timothy Ehmann:** That's a very good question. I probably do not know the answer to it. I'm a physician, not a lawyer or a parliamentarian.

I think that fundamentally my position is that I'm concerned about requesting physicians to consider death as a treatment, as part of their routine practice. I think it's very dangerous for our profession. It puts patients at risk in general.

I'm quite concerned as a psychiatrist, seeing what's happened with adult legislation under the current regime. We were promised that the mentally ill were not going to be involved. It's going to be opening up to them. I'm concerned that this is going to be moving very quickly to my patient group, which is children and adolescents with mental illnesses. That's a very dangerous group to offer MAID to.

[Translation]

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator. You have 20 seconds left, but that isn't enough to continue.

[English]

We have Senator Kutcher, please, for two minutes.

**Hon. Stanley Kutcher:** Thank you, Chair.

Ms. Marcoux, thank you very much for your personal testimony. As someone who has consulted to pediatric oncology wards, your story rings exceedingly true with me.

In a previous session, a witness who is a MAID provider told us that all of those who have chosen MAID have died a good death. You and your son considered MAID, but it was not available to him. Had it been available to him, do you think his death may have been better, as he would have been conscious until the moment he

died, or do you think he would have preferred to stay in palliative sedation?

[Translation]

**Mrs. Caroline Marcoux:** I think he would have preferred to bring his death forward by a few days. Ultimately, it was a matter of days. He died two or three weeks after requesting palliative sedation. It was not very long after.

Medical assistance in dying would probably have meant he did not have to live the last few days, which were not easy for him. He had some very bad nights, he had nightmares, the pain was constant and he no longer had any quality of life. Even with the palliative sedation, he didn't seem well. He fidgeted constantly. When someone spoke to him, he reacted, in a way, as if he wanted to answer; he couldn't speak, but he mumbled. He didn't seem to be in a deep, calm sleep after receiving the palliative sedation. If he had had access to medical assistance in dying, he could have avoided those last few days, and especially the final day, which he spent under sedation.

[English]

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Kutcher.

Go ahead, Senator Dalphond.

[Translation]

**Hon. Pierre Dalphond:** My question is for you, Ms. Marcoux.

When your son Charles asked for palliative sedation, did the doctors refuse? Did they tell him he didn't have the capacity to consent and he had to have his parents' consent? Did they ask him whether he was sure that was really what he wanted?

**Mrs. Caroline Marcoux:** No, not at all. In fact, yes, under the protocol, they had to ask him to confirm that it was really what he wanted. The last few days, the doctor kept asking him the question. The final week, he asked him whether he was ready, if it was time for the sedation. The day when Charles said it was that day that he wanted the sedation, he was completely certain. That was the day he wanted to go to sleep.

Before giving the injections, the doctor asked him again to confirm that this was his decision, following the whole protocol.

**Hon. Pierre Dalphond:** So no one questioned his capacity.

**Mrs. Caroline Marcoux:** Absolutely not.

**Hon. Pierre Dalphond:** Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Dalphond.

[English]

We'll now go to Senator Wallin.

• (2015)

**Hon. Pamela Wallin:** Thank you very much.

Dr. Ehmann, you have said that refusing life-saving treatment is fundamentally different from MAID, but both are designed to alleviate pain and hasten death, so the end result is the same. Why do you make the distinction?

**Dr. Timothy Ehmann:** I make the distinction because the journey to get there is quite different. When a life-sustaining treatment is refused, the physicians are not actively participating in terms of the demise of the patient in a direct way. They are following patients' instructions—

**Hon. Pamela Wallin:** That's what I'm asking about, because it seems to be about the position of the physician, not about the actual patient.

**Dr. Timothy Ehmann:** Right. The role for us as physicians is, I believe the phrase is “to cure sometimes, to relieve often, to comfort always”. It's something along that line. Essentially the problem is that when the physician actually becomes part of the death process, particularly for non-dying patients, to whom we're starting to see MAID being offered, I have grave concerns about that. Even for someone close to death we have palliative care.

**Hon. Pamela Wallin:** Do you think the doctor's views are actually more important than the patient's views? I guess that's what I'm asking.

**Dr. Timothy Ehmann:** In my practice working with children and adolescents, I take into consideration everyone's views, and we're all working towards the best interests of the child and the adolescent.

**Hon. Pamela Wallin:** I'm out of time here, but I take it you are opposed to MAID period, not just for youth or for those with mental illness.

**Dr. Timothy Ehmann:** As a physician, I'm opposed to MAID and to having our profession deliver this.

**Hon. Pamela Wallin:** Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Wallin.

Senator Martin.

**The Joint Chair (Hon. Yonah Martin):** Thank you very much.

I want to add my voice to others' voices to say that the courage you have shown in sharing your personal story is really admirable, Ms. Marcoux.

My question is for Dr. McCormick. Charles was an exceptional teenager, and there are other exceptional mature minors, but as you stated, most youth are not aware of the various treatment options they have; nor do they have an accurate understanding of them. Particularly with indigenous youth, what suggestions do you have

for overcoming the barriers they face in obtaining the help they need?

**Dr. Roderick McCormick:** I should also clarify that I'm not opposed to MAID in track one, in particular for adults. The death of my sister-in-law actually was inevitable and the cancer had spread to her throat, so she was at risk of choking to death when she received MAID.

I am opposed to it for mental illness and for minors, particularly for mental illness.

What we could be doing, first of all, is talking to youth. In talking to indigenous youth without consulting with us properly, there will be legal cases I'm sure, because that is a right under UNDRIP.

But let's spend some money on mental health. This is the poor cousin of the health field. We don't spend money on it. Provide accessible diagnosis and treatment centres and mental health navigators; get rid of the jurisdictional game; fund Jordan's principle properly, provide life skills training to youth on how to problem solve and how to express emotions; provide services that others get, like palliative care, provide training and support to frontline workers, develop peer support programs for youth.

I could go on and on. There is so much that needs to be done, and we don't do it. Everything is at the “postvention” stage, not at the prevention stage. It's a crisis-oriented health care system for indigenous people.

**The Joint Chair (Hon. Yonah Martin):** Thank you very much.

**The Joint Chair (Hon. Marc Garneau):** Thank you very much to our three panellists this evening. It is important for us to recognize that providing your testimony this evening involves making very personal statements about what you believe and that takes courage as well. It is important for us, as members of this committee, with very difficult work ahead of us to hear from all of you.

[*Translation*]

Thanks to all of you for taking the time to answer our questions and providing your very personal testimony. We are very grateful.

Have a great evening.

[*English*]

With that, the meeting is adjourned.





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