



OFFICIAL REPORT
AITHISG OIFIGEIL

DRAFT

Health, Social Care and Sport Committee

Monday 11 November 2024

Session 6



The Scottish Parliament
Pàrlamaid na h-Alba

© Parliamentary copyright. Scottish Parliamentary Corporate Body

Information on the Scottish Parliament's copyright policy can be found on the website - www.parliament.scot or by contacting Public Information on 0131 348 5000

Monday 11 November 2024

CONTENTS

	Col.
DECISION ON TAKING BUSINESS IN PRIVATE	1
ASSISTED DYING FOR TERMINALLY ILL ADULTS (SCOTLAND) BILL: STAGE 1	2

HEALTH, SOCIAL CARE AND SPORT COMMITTEE
30th Meeting 2024, Session 6

CONVENER

*Clare Haughey (Rutherglen) (SNP)

DEPUTY CONVENER

*Paul Sweeney (Glasgow) (Lab)

COMMITTEE MEMBERS

*Joe FitzPatrick (Dundee City West) (SNP)

*Sandesh Gulhane (Glasgow) (Con)

*Emma Harper (South Scotland) (SNP)

*Gillian Mackay (Central Scotland) (Green)

*Carol Mochan (South Scotland) (Lab)

*David Torrance (Kirkcaldy) (SNP)

*Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP)

*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Dr Ramona Coelho

Dr Stefanie Green (Canadian Association of MAiD Assessors and Providers)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament
Health, Social Care and Sport
Committee

Monday 11 November 2024

[The Convener opened the meeting at 17:00]

Decision on Taking Business in
Private

The Convener (Clare Haughey): Good evening, and welcome to the 30th meeting of the Health, Social Care and Sport Committee in 2024. I have received no apologies.

The first item on our agenda is a decision on whether to take agenda item 3 in private. Do members agree to do so?

Members indicated agreement.

Assisted Dying for Terminally Ill
Adults (Scotland) Bill: Stage 1

17:00

The Convener: The second item on our agenda is our continuing scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill at stage 1. Today, we have an evidence-taking session with people who are involved in the application of assisted dying law in Canada. All of our witnesses are appearing remotely.

I welcome Dr Ramona Coelho, who is a physician and member of the medical assistance in dying death review committee of Ontario, Canada, and who joins us in a personal capacity and not on behalf of any organisation. I also welcome Dr Stefanie Green, who is a medical assistance in dying practitioner, founding president of the Canadian Association of MAiD Assessors and Providers—CAMAP—and an adviser to the British Columbia Ministry of Health. I thank you both for joining us today.

We will move straight to questions, the first of which is from Paul Sweeney.

Paul Sweeney (Glasgow) (Lab): Thank you for joining us this evening. I am not sure what the time difference is—it might be early in the afternoon at your end. I appreciate the time that you are giving us.

Dr Green, is there any evidence that poor palliative care is acting as a driver for people in Canada seeking assisted death?

Dr Stefanie Green (Canadian Association of MAiD Assessors and Providers): Thank you for the invitation to speak to the committee today. I appreciate the question, and I am happy to tell you that we now have eight years of experience in Canada and more than six years' worth of data to look at.

Palliative care and MAiD are not mutually exclusive. We have actually seen an upward shift in the number of palliative care doctors who are involved in MAiD. To specifically answer your question about whether poor access to palliative care is a driver of MAiD in Canada, I am happy to say that we have good data showing us quite the opposite.

We gather information from our national reports in which practitioners talk about whether their patients have had access to, or are receiving, palliative care and from our provincial reports, which are based on nurse investigators from coroners' offices speaking to families and combing through reports. From those sources, we can see that 96 per cent of people who have received

MAID in Canada have had access to palliative care and that roughly 80 per cent of them are receiving palliative care at the time of their MAID death. You cannot really look at those numbers and conclude that MAID is driven to any degree by a lack of access to palliative care.

That data is clear, but there is also something else to consider. We know from a lot of data that, especially in Canada, people with cancer will get better access to palliative care than people with other diagnoses. In Ontario, they are twice as likely to receive palliative care. We know that they get palliative care earlier—the median length of time it takes for them to receive that care before death is three months as opposed to three weeks.

Further, we know that the palliative care that those people receive will be of better quality—they are four times as likely to receive palliative care at home as are people with other diagnoses. Two patients—one with lung cancer and one with a lung disease such as emphysema or chronic obstructive pulmonary disease—will have essentially the same symptoms and will potentially be experiencing the same degree of suffering, but the one with cancer will be receiving substantially better palliative care. If you believed that access to palliative care would reduce the incidence of assisted dying, you would expect a dramatically lower incidence of MAID in the group that is receiving the better palliative care. In fact, we see the exact opposite in the data. In Canada, more people with cancer than people in any other group are asking for and receiving medical assistance in dying. It is simply not possible to conclude that MAID is being driven to any degree by a lack of access to palliative care.

Paul Sweeney: Thank you. Dr Coelho, do you have any response to the question?

Dr Ramona Coelho: Yes. Thanks for having me here. I reached out to the Canadian Society of Palliative Medicine, and my statements are based on what its board told me. They are all evidence based, and I am willing to submit the evidence after this session.

Palliative care is different from MAID in that it sets out to handle existential physical and mental suffering and look for physical supports to help a person to live well—it does not seek to hasten death. The two things are ethically distinct. Palliative care should be a clinical and legal safeguard that prevents people from feeling driven to, or desperate to choose, medical assistance in dying. However, in the words of the CSPM, we are seeing

“the diversion of limited palliative care resources to support MAID, and the potential for patients refusing palliative care services for fear it will hasten their death.”

We note that there is a power imbalance between healthcare professionals and patients, and we believe that the fact that healthcare professionals in Canada are raising the option of MAID unsolicited might result in undue influence being brought to bear on people who lack support and feel that they might be a burden, which might make them consider that they would be better off dead—in other words, coercion.

The committee that I am part of has studied the coroners' reports that were released in October to look for trends and cases in the health records. Before I talk about that, though, I will digress a little to tell you that an investigative journalist, Alexander Raikin, who is about to publish an article—within a day—in *The New Atlantis*, has given me access to all the reports from the chief coroner of Ontario from 2016, 2018 and 2020 until now, which include data from before the expansion of MAID. I can say more about that later.

Returning to the issue of the power imbalance and of the unsolicited raising of the issue of MAID by medical practitioners, I note that access to palliative care depends on medical diagnosis—as Dr Green said—and on where someone lives and their socioeconomic status. Therefore, indigenous, incarcerated and homeless people, as well as disabled people and children, get lower-quality palliative care. Multiple studies, which I can submit, have shown that people who lack of access to palliative care and have a high symptom burden are among those who are granted MAID in Canada.

The accuracy of Government reporting about the provision of palliative care has been called into question by many palliative care experts in Canada because the data is based on MAID providers ticking a box to say that palliative care was provided. That is not gathering information about the length or quality of palliative care. In one case that I reviewed the health records of, which involves a battery charge that is going to court, the box to say that palliative care was provided was ticked by the MAID provider but I did not see that there had been a palliative care consultation. However, even though the Health Canada reports are extremely flawed in their process of data gathering, they still report that 21 per cent of patients received palliative care for only two weeks before they received MAID, which is likely inadequate and means that they were likely granted palliative care only after they requested MAID.

Choosing to die from MAID in the face of a lack of timely and quality palliative care and supportive services is not a choice and should be considered a medical error. Polls show that the majority of Canadians prioritise expanding palliative care

services over MAID and that they are concerned that MAID will replace social services.

The Convener: Dr Green wants to come back in.

Dr Green: Just so that you know, we can barely hear you through the microphones that you are using in the committee room.

I appreciate the chance to talk again. As far as possible, I will keep my remarks short, concise and evidence based and not based on anecdote, a flashy headline or a report here or there.

I want to address the comment about there having been a reduction in funding or a diversion of resources away from palliative care to MAID. That is wholly false. Since 2016, when our medical assistance in dying law was passed, palliative care has enjoyed probably its greatest increase in utilisation in Canadian history, with dramatic new investment in palliative care by our Government. I will provide just a few examples. In 2016, the federal Government invested \$3 billion in home care as part of the new health accords—that would have been a big boon to home palliative care. Last year, Health Canada gave the Pan-Canadian Palliative Care Research Collaborative \$2.5 million for advancing research and building research capacity. In 2020, the Alberta Government gave several million dollars in funding to the palliative institute at Covenant Health to work on advanced care planning. We have seen an unprecedented increase in palliative care staffing levels in most parts of the country. In Ottawa, one hospital's palliative care division has more than doubled in size since 2018. In Ontario—our largest province—the number of community hospice beds has essentially doubled since 2016.

One simply cannot say that resources have been diverted from palliative care to MAID. In fact, as in every other legal jurisdiction in the world where we see assisted dying provision, the funding and levels of palliative care have increased since that became legal.

Paul Sweeney: I will move the discussion on. How have palliative care providers in Canada received the legislation since its introduction, in 2016? To what extent has assisted dying been integrated into existing care pathways, and how do they interface?

Dr Coelho: Who is your question directed to?

Paul Sweeney: I put the question to Dr Green in the first instance, then to Dr Coelho.

Dr Green: In the beginning, there was a lot of fear and a lot of pushback from the palliative care community. There was a lack of understanding of what MAID is, not just in the palliative care community but in the entire healthcare community.

National polls show that, although the great majority of Canadians—more than 80 per cent—have consistently, year after year, supported assisted dying, the rates of support are lower in the healthcare community. That is seen across jurisdictions as well.

There was some—I will be polite—reluctance in the palliative care community to accept MAID. I believe—I and others have seen this through reports—that palliative care doctors are the most patient-centred clinicians in healthcare. That is part of their ethos. I fully respect that, and I think that that is incredible. It is patients who have brought palliative care doctors to this work.

I have heard many hospices and palliative care communities say, in the beginning, that they would simply not do this work. That is respected—our law, of course, allows for conscientious objection or any reason to object to doing the work. However, as clinicians saw their patients asking for information about assisted dying, they would learn a little bit about it. They would counsel them about what they thought it was and leave the work to someone else, like me. They then found that they had very strong relationships with their patients who were asking for such care, and, slowly, we saw them beginning to do assessments for assisted dying while leaving its provision to others—people like me.

Today, more and more palliative care doctors are doing provision as well. There has been a slow change. There are still pockets of people who are absolutely unwilling to do the work, and that is fine, although I think that it is not to the benefit of the patient. The Canadian Association of MAiD Assessors and Providers, which is the group with which I am associated, has around 600 members, and the last time that we surveyed them was probably about two years ago. Of all of our clinician members, maybe 75 per cent do the work of assisted dying and 16 per cent self-identify as palliative care practitioners. In Ontario, a very low number of palliative care doctors were doing the work, but around 10 per cent of all MAID deaths in Ontario are now being provided by palliative care doctors. The numbers are still small, but we will see them change over time, because patients are driving that.

Dr Coelho: Again, I am speaking on behalf of the Canadian palliative care society and I will send all the evidence to back up what I say.

The coroners' reports that just came out of Ontario list the trends and statistics for 2023 and show that palliative care access is at only 40 per cent despite all the funding—I do not know where it is going. The position on home care is even worse. Dr Dave Henderson of the Nova Scotia Health Authority testified during the committee hearings in Canada that, in many places, there is

no palliative care and that MAID is the only option. He said that he was asked to train MAID assessors on the principles of palliative care but that, in the end, they found that it is too comprehensive and is not what they are about. I can also send you all the evidence from the Parliament of Canada.

Therefore, I disagree.

Paul Sweeney: If you had the opportunity to amend the current palliative care legislation in Canada, what would you want to change? I put that question to Dr Coelho.

Dr Coelho: Palliative care should be a health right. It should not be the case that people are so desperate and that it takes so long to get palliative care. Again, in Ontario, the coroners' stat that came out in July is that, on average, it took 2.2 days to access the MAID team and to have a MAID assessor. That speaks well to the MAID team—I am not saying anything about that. However, when services take weeks, months or years to access, people get more desperate. If we are talking about autonomy, the choice to die should not be driven by people having no other options.

17:15

Paul Sweeney: Dr Green, are you content with the current Canadian legislation, or would you seek to amend it, strengthen it or change it in any way?

Dr Green: I commend it for recognising conscientious rights, which I think is very important. I also commend it for requiring practitioners such as me to raise the issue of palliative care, to explain what it is and to offer it to every MAID requester. That is very important as well, and we certainly do it, which is why the numbers show that the levels of palliative care provision are so high among our patients.

The only change that I would like to see, if I could wave a magic wand, is a recognition that, although practitioners and other people have conscientious rights, bricks and mortar do not. It is probably not good that tax-funded institutions can choose to opt out of a legally covered MAID service in Canada, so palliative care facilities should not have the right to opt out. That is certainly the state of affairs in Quebec, and I think that the rest of the country should adopt that policy.

I recognise that, over the past eight years, the infrastructure for MAID has, in some places, been built up to such a point that those places are more efficient than others. However, I do not think that that is an argument against the policy. I think that we need to focus our attention on making sure that

every Canadian has access to good-quality palliative care, not on reducing access to MAID.

Brian Whittle (South Scotland) (Con): Thank you, Dr Coelho and Dr Green, for taking the time to speak to us. My question, which is a brief follow-up to my colleague's question, concerns something that Dr Green hinted at. If a patient who presents to a doctor asks for MAID, is the doctor required to suggest palliative care as an alternative option? If so, is that requirement universal across Canada? I ask Dr Coelho to respond first.

Dr Coelho: The legislation says that a doctor should inform a patient about all their options. In reality, a review of the coroners' reports, which we have sent to you, shows that the options that are offered depend on what the MAID provider or the doctor has expertise in. It might be that a patient has raised the issue with their family doctor, who might have a limited understanding of care systems, which might result in a patient not knowing that they have the option of accessing palliative care. Alternatively, palliative care might be inaccessible because of rurality, because the person is homeless or for some other reason. Although the law says that a patient is meant to be informed of their options, those options do not have to be accessible.

Brian Whittle: Dr Green, you suggested that it is a doctor's responsibility to introduce the option of palliative care if a patient requests MAID. Is that approach universal across Canada, and is that provision consistent?

Dr Green: I would say so. The requirements regarding what must be done by any MAID practitioner—not a family doctor or an oncologist—who is asked to do an assessment for MAID are laid out in the criminal code of our country. We are very aware of what we are required to do and of the penalty for not doing it. On top of that, there are provincial standards of practice that we must adhere to, all of which require us to raise the option of palliative care with our patients and document that we have done so. I believe that that is happening across the country. We teach practitioners to do that, they are aware of the law and they are aware of the practice standards. We see in the numbers in the national reporting that that is happening. Every case must be monitored and reported in annual reports, and we see those high numbers of patients accessing and receiving palliative care because of that requirement. I do not think that there is any other explanation for it.

Dr Coelho: I would like to comment, if I may.

Brian Whittle: Go ahead.

Dr Coelho: Thank you. I understand what Dr Green is saying, but, as Dr Green was the president of CAMAP and would have had access

to the coroners' reports that I mentioned, she would know that there were violations of compliance in 2016 and 2017 to the point where the chief coroner gave a talk saying that he could not continue just providing education following non-compliance and that, instead, he would introduce a levels system.

The reports for the jurisdiction of Ontario—which I think has the best oversight—show that there were more than 400 violations. I have not seen any public reports from British Columbia. The end-of-life commission in Quebec does a good job of getting statistics and, regarding palliative care, which is relevant here, it released a report two weeks ago that showed that the MAID death rate in the province is now 7.3 per cent and that it cannot determine, from the data collected, whether palliative care was administered or, if it was, whether it was adequate. As I mentioned, the Health Canada reports are based on self-ticked check boxes and are unlikely to reveal non-compliance with the law or abuses.

Our review of the cases that I have mentioned—our team has gone through the charts—shows that the rate of palliative care is much lower than has been suggested. That fits with other academic studies that have been done by palliative care doctors on the quality of palliative care and the services that are being offered to patients before medical assistance in dying.

Gillian Mackay (Central Scotland) (Green): Good evening. In 2019, the United Nations special rapporteur on the rights of persons with disabilities expressed significant concerns about Canada's approach to medical assistance in dying, particularly from a disability perspective. She noted the absence of a protocol to ensure that people with disabilities were offered viable alternatives before considering assisted dying. That concern was heightened when the federal Government passed bill C-7 in 2021, which relaxed safeguards for patients eligible for MAID, including the removal of the 10-day waiting period and the requirement to offer palliative care options. Most recently, the Office of the Chief Coroner of Ontario published the "MAiD Death Review Committee Report 2024", which indicated that many individuals are seeking MAID due to factors that are unrelated to medical illness, such as homelessness and isolation, with MAID access notably higher in economically disadvantaged neighbourhoods.

Given the alarm that has been generated worldwide by Canada's experience, do you believe that characterisation to be accurate, and have specific protocols or safeguards been introduced to prevent individuals from turning to MAID due to a lack of social support or access to complex care? I ask Dr Green to comment first.

Dr Green: I think that we should probably dive into the coroners' reports. They have been mentioned several times and I relish the opportunity to look at that data with you.

You have repeated some of the headlines from the international news and some of the opinion pieces that have been published. I would like to clarify that the death review committee reports are not showing and not saying the things that you have suggested that they are. In fact, they show quite the opposite. The death review committee reports show that MAID recipients are in fact substantially less marginalised than people who die without MAID, and that, at least in Ontario, those who die with MAID under track 2 specifically are no more marginalised than people who die naturally or with chronic illness. Nowhere did the report make the conclusion that you have suggested it did. There are people who sit on the review committee who believe that the data makes that conclusion. There is a diversity of opinion among the committee members, and the committee report documents that there is a multiplicity of conclusions, but the committee did not conclude the things that one or two people are suggesting that it did, and to suggest otherwise is disrespectful of the committee and disingenuous at best.

It is important that, when you read data, you do not misunderstand because of a lack of basic data literacy. I will very briefly and simply explain the position to you. If you study a group of people who go to see a neurosurgeon, you will probably discover higher mortality rates in that group of people than in other groups. More of them will die than will be the case in the general population, but that does not mean that seeing a neurosurgeon increases your risk of dying. Intuitively, we know that that is not true. That would not be a fair comparison. Neurosurgeons see people who are already at significant risk of dying as they have significant neurological problems such as brain cancer. If a study compared people with the same brain cancer, half of whom saw a neurologist and followed their recommendations and half of whom did not, you could use that to compare outcomes and try to determine whether seeing a neurologist or neurosurgeon affects mortality rates. It is called the cohort effect, and it is one of the most basic elements that must be borne in mind when reading data.

The same thing applies when you look at patients who die on track 2 of MAID in Canada. If you are trying to determine whether higher levels of marginalisation are leading people to MAID, you do not only look at marginalisation levels in those who have track 1 and track 2 MAID. That would not make sense. For the exact same reason that I talked about in relation to the neurosurgeon example, you must compare people with the same

diagnosis who did and did not receive MAID. When we look at people with diagnoses that lead to track 2 MAID, such as chronic pain or neurological illnesses, which is the number 1 diagnosis that leads people to track 2 MAID, and compare those who did and did not receive track 2 MAID, we do not see higher levels of marginalisation in those who receive track 2 MAID. The coroners' reports are extremely convincing and reassuring in relation to that matter.

It is important, then, that we understand that it is the underlying illness itself that is associated with higher rates of marginalisation. Socioeconomic deprivation drives mortality; we know that from lots of other studies, and it is not news, but there is no evidence in these reports to show that that is what is driving assisted dying. We should be focused on reducing factors that lead to socioeconomic deprivation, not on trying to reduce MAID. The reports are very reassuring.

Gillian Mackay: Dr—

Dr Coelho: Do I get a chance to weigh in here?

Gillian Mackay: Yes.

Dr Coelho: Thank you.

First of all, that was very interesting analysis from Dr Green. My husband, who is an epidemiologist and staff in health research methods at McMaster University, has also looked through this matter, too, and I would welcome it if Dr Green submitted her evidence about the trends.

The trends are there, and they show that people in track 2 are less likely to have next of kin, which means that they will often list a lawyer or their medical practitioner as their next of kin. That speaks to a lack of social support. Secondly, the rate is higher among women than it is among men, which mirrors the findings in the—*[Interruption.]* Yes, Dr Green—the figure is 61 per cent. It mirrors increased suicidality in women; I am not sure whether you in Scotland have seen the article in *Glamour* on how women face higher rates of domestic abuse, rape, trauma and financial marginalisation. If you look at certain European countries that have MAID outside the end-of-life context, you will see that those people, if they have attempted suicide, would do well with suicide prevention and care, and yet they are having their lives ended.

That is what the UN is concerned about—that we are ending the lives of people who would have benefited from suicide prevention, but now we are seeing them as MAID-able. The president of the Canadian Association of MAiD Assessors and Providers, in an interview with Meagan Gillmore in 2023 that I can send you, said, “You know, yes, I understand. I live in Ontario now. The people are

being approved for MAID on the basis of psychosocial suffering, and they have a disability, but they don't have to be tied together. The intolerable suffering does not need to be related to the disease. So yes, they can choose death for the psychosocial suffering.”

Last month in the Associated Press, Maria Cheng and Angie Wang released what was going on in CAMAP forums, showing that MAID providers were concerned not about the legality of killing somebody in poverty who had a disability, but more about how the press would react to it. The president of CAMAP responded by saying that MAID for psychosocial suffering was forbidden. Therefore, when it comes to trying to square those two comments, my understanding is that if you have a disability and psychosocial suffering, it is okay to die, according to the legislation.

If you look at the six cases portrayed in the coroners' reports, you will see that they actually involve incredibly marginalised people. The first gentleman in the vulnerability case has largely untreated mental ill health and addictions, and happens to have inflammatory bowel disease. He goes to see a psychiatrist who raises MAID with him as an option; he starts his MAID journey; the family are concerned, but they are not consulted; and the MAID provider drives him to the place of the MAID provision. There are clear signs of borders being crossed and undue influence.

The second case is of a woman who has disabilities and multiple chemical sensitivities. Because she is poor, she lives in housing surrounded by smells of smoke, marijuana and so. Although she gets funding to make her apartment better, she is still in this tiny space and isolated, and she says that she chose MAID, because of her housing situation.

17:30

The last situation involved a gentleman who had an injury during Covid. He was isolated from his family and scared about whether he would ever be able to return to them or would ever be able to parent his children. He received MAID at a time when it is known that suicidality is high. People who take care of people with disabilities know that suicide rates are high among those who have a new injury, but if those people are cared for, suicidality drops and mirrors that in the general population. That gentleman received MAID at a time of transition, and a legislative requirement was not fulfilled, in that there was no expert involved in the MAID assessment.

Dr Green said that the reports are reassuring, but I would encourage people to read them to see what they say.

Gillian Mackay: Thank you. I ask our witnesses to focus on the content of my second question and to keep their answers as succinct as possible, because I know that other members want to come in. I am interested to hear your perspectives on the key challenges that Canada faced in adopting its approach. How might we in Scotland learn from those experiences as we work to develop our own legislation?

Dr Green: I commend you for learning from other jurisdictions; we in Canada have certainly done so. We learned from our colleagues in Europe, the States and other places so that we could craft a better system.

The number 1 issue that you would benefit from learning from is the fact that the biggest mistake that we made in Canada was that we did not have an implementation period. MAID became possible in Canada not through voter demand or through any Government thinking that it was a good idea; it came through the courts. As I am sure that you are aware, it came as a result of constitutional court challenges. Once it became a legal possibility in Canada, we did not take the time to train up clinicians and to get the infrastructure ready, in the way that the Australians did. Because of that, the process was a bit patchwork in the beginning, and we had to learn on the fly. That would be the biggest thing that I would change.

I will keep my comments concise. There are at least four comments that I would like to make in response to the previous comments, but I will simply address the point about the sex differences, on which the position is so stark. It is the exact same point as the one that I made about people who go to see a neurosurgeon. We can see by looking at the breakdown of the diagnoses that are involved that any sex differences that are observed in track 2 of MAID in Canada are easily explained by the sex differences in the conditions. The most common of the neurological conditions that lead to track 2 is Parkinson's, which occurs almost twice as often in men as it does in women. In track 2, the provision of MAID for neurological conditions is more common for men than it is for women. That makes sense because we know what is driving it.

If we look at MAID track 2 for comorbidities or the "other" category, we see that the number 1 illness there is frailty, which is twice as common in women as it is in men. It is true that, for those conditions, we see more women than men. Other than those two, there are no sex differences between track 2 conditions that lead to MAID.

Gillian Mackay: Dr Coelho, what are the key considerations and challenges that we should be looking at here in Scotland?

Dr Coelho: Could you repeat the question? Were you asking about track 2?

Gillian Mackay: No. I would like to hear about the key considerations and challenges that Canada faced in adopting its approach and how we might learn from those in Scotland.

Dr Coelho: I think that having a balanced panel of people informing the Government would have greatly helped with the balancing of safety and patient access. Our Government funds the Canadian Association of MAiD Assessors and Providers, which is an advocacy group, to develop a curriculum. People who have been outspoken about access in a very broad way have been leading the consultations. In our Government consultations, many senators and MPs admitted that they had consulted Jocelyn Downie for information on how to do this. James Maloney, who is a member of Parliament, asked me to get in contact with Health Canada about my concerns about safety, because, for the past 17 years of practice, I have taken care of marginalised patients and dealt with death wishes. However, Health Canada never reached out to anybody I know who deals with chronic care for marginalised people; instead, it relied on the evidence of MAID practitioners.

I can give a brief example. The palliative care founder Dr Leonie Herx stated in Parliament that she was already seeing concern about capacity. Dr Herx has done training in neurology and family medicine. She said that MAID assessors and providers said that patients who did not have capacity had capacity without a capacity assessment being carried out and were approving them for MAID.

Dr Herx was chided by an MP for making unprofessional accusations of malpractice that should have been sent to the police or the College of Physicians and Surgeons of Ontario. We now know that, in 2020, the chief coroner of Ontario actually gave a presentation to CAMAP, when Dr Green was the president, and explained that one of the concerning trends was that there were no formal assessments of capacity in the charts and yet patients had previously been deemed to not have capacity, but there was no way to correlate what really happened, because the patient was dead.

Carol Mochan (South Scotland) (Lab): I thank our guests for agreeing to speak to us. Much of what I am going to ask about might have been covered but, in the interests of clarity, I will ask my question, which is about the recorded numbers. We know that the Government has to report on anyone who has accessed MAID. Could you give us a sense of where you think the numbers are in terms of what was anticipated prior to the legislation? We see that there was a rise between

2019 and 2022. Have you considered what might have caused that rise? Can you give us some sense of the situation in Canada in terms of the actual numbers? I ask Dr Green to respond first.

Dr Green: There have certainly been lots of headlines about increasing numbers, calling the rise “shocking” or “disturbing”. However, the numbers of people seeking assisted dying in Canada are entirely as expected. They are not at all surprising or a sign of anything nefarious occurring.

Rates of assisted dying in Canada are sometimes compared with those in Oregon or California, which are states where the percentages of annual deaths attributed to assisted dying are significantly lower. That is not a reasonable comparison—I refer you to the cohort effect issue that I mentioned earlier. Laws and requirements in Oregon and California are significantly different from those in Canada. For example, they require the person to be suffering from a terminal illness, they require self-administration and there are a number of other issues that will significantly reduce the number of people who will be eligible for MAID. A better comparison with Canada is the Netherlands, whose law is similar to ours. It does not require the person to be suffering a terminal illness and, importantly, it allows clinicians to administer the death, so it does not discriminate against those who have become disabled due to their illness or were disabled to begin with. That means that there is a larger pool of people who might access this care. Our laws are similar and our medications protocols are similar, so I think that that is a fair comparison.

In the Netherlands, which has 20 years of experience, the percentage of annual deaths that are attributed to assisted dying is anywhere between 5 and 5.5 per cent of all annual deaths. In Canada, after eight years of experience, we have data for the first six years and we can see that the number of deaths that are attributed to assisted dying is 4.1 per cent of all annual deaths, so we are not yet as high as our colleagues in the Netherlands—not that we are trying to catch up with them or anything.

Of course, in the beginning, the level will be 1 per cent, and it will grow to 2 per cent and then, over the years, reach 4 per cent. You have to consider the fact that the patient population has to become aware of the service—in the beginning, many people were not even clear that assisted dying was legal. You then have to build the infrastructure and put it in place—as I said, many provinces did not have an implementation plan and did not start implementing any infrastructure until well after the law was in place. You have to have clinicians who are not only trained but involved in the service. A number of things have to

happen in order for the greater population to have access to this care. Seeing the numbers climb over the years is absolutely expected, as it would be with any other medical care that is introduced into the system, and our numbers remain lower than those in any country with a comparable law.

I am also compelled to point out that actual numbers are irrelevant, of course, because there is a value judgment being added here. Let us say that we believe that heart attacks are bad. If the rate of heart attacks is increasing, we should be worried about that and try to do something to bring it down, but that is because we have made a somewhat non-controversial value judgment that heart attacks are bad. If you think that assisted dying is bad, there is no good number. The right number—if you can call it that—is reached after all of those who request the care receive a rigorous assessment, which includes an exploration of their reasons and the alternatives, such as palliative care and the offer of other resources, which are all required by our law. Some of them are found to be eligible, and that remaining group of people are then able to access and receive the care. That is the right number. It is a question of choice, not a question of number.

Carol Mochan: Dr Coelho, would you like to respond?

Dr Coelho: I am from Quebec, so I was there when Quebec initially decided to go forward with expanding its approach, and I participated in the Select Committee on Dying with Dignity. Gaétan Barrette, a Quebec politician at that time, estimated that there would be fewer than 100 requests per year, that it would be an exceptional procedure for people for whom there was nothing left to be offered, and that, for sure, palliative care would be a safeguard. Now, in Ontario—I have shifted provinces and, actually, Quebec has a higher rate, at 7.3 per cent—we are averaging 400 cases of completed MAID a month; there were 4,600 in 2023. If you look at the provincial tallies that have come in for 2023, even though we are still expecting our Health Canada report, we are at around 15,300, I think.

I agree with Dr Green that the numbers do not matter per se, but I reiterate that the numbers matter if the decision is driven by desperation. Suicide prevention is still a priority for our Canadian society. I am very concerned—let me give a disclaimer; I work in a place with poor people who have poor access—to see atrocious cases of MAID being approved that make me very sad. When I joined the coroner’s committee, I was shocked. The cases that we released are very similar to the cases that I see where I practise, and the coroner chose those cases for us to review because they are recurrent practice patterns. In those batches of cases, you can

clearly see that people who do not have other options are choosing MAID, which is very worrisome to me.

Therefore, the numbers are worrisome to me, but they are the result of a lot of health and policy societal failures that make people desperate. If MAID is to be safe, it has to be safeguarded.

Carol Mochan: Thank you. I think that some other colleagues have questions around safeguarding, so I will go back to the convener.

The Convener: Thank you. I am very conscious of the time, so I ask colleagues to keep their questions concise and our panel members to keep their answers concise and to the point.

Before I ask my questions, I put on record that my entry in the register of members' interests shows that I hold a bank nurse contract with NHS Greater Glasgow and Clyde.

How confident are you that there is an adequate evidence base for the substances used in assisted dying in Canada?

Dr Green: That is an interesting question. There is absolutely no evidence whatsoever, because the drugs were not used for that purpose beforehand. There are no randomised control studies, data or published bodies of evidence for that particular use.

Evidence does not exist, except for what we know from the Netherlands. We have used their IV protocol, for which they have 20 years of data, and we see no complications with it. The substance is 100 per cent effective when it is in the intravascular system. We know that from the Netherlands and from our own experience.

I think that you are perhaps alluding to some odd comments by a clinician in the United States, who talks about different drugs.

The Convener: No, I am not alluding to any comments. It is a question that I asked colleagues from Australia.

Dr Green: Then I would point you towards CAMAP's rigorously reviewed papers on the IV protocol and the oral protocol that is used in Canada, where it comes from, why it is used and the background information for it.

The Convener: Thanks. When there are complications—if there are complications—are professionals allowed to intervene? What training do they receive on how to respond?

Dr Green: As you probably know, 99.9 per cent of all cases of MAID in Canada are clinician administered, and they are intravenously administered. As I said, when we are in the vein there is 100 per cent success rate. There are no

failures that way unless you blow the vein, in which case you have to create IV access.

In terms of oral MAID, there is the potential for failure. However, we have fewer than 30 cases across the country, so I do not think that they are helpful. We could look to our colleagues in Australia, where they have hundreds of cases and a 0 per cent failure rate.

However, in answer to your question, in British Columbia, which is the province that I work in, MAID practitioners are required to be present during the MAID provision, whether it is intravenous or oral. That is to ensure that things go safely and well, and that, if there is a complication, we have the opportunity to step in to rectify the issue. There is zero evidence of complications with IV MAID and few with oral.

17:45

The Convener: In terms of the security and safety of where substances are kept, am I correct in thinking that the administering physician or healthcare professional is responsible for ensuring the security and safety of the drugs prior to use?

Dr Green: Yes. I am required to actually go to the pharmacy to pick up, sign for and check the drugs. I take them to the patient and administer them or watch the patient administer them for themselves, and I must take that back to the pharmacy and sign off again. I am legally responsible for the medications, and I sign for them. So, yes, that is correct.

The Convener: Grand—thank you very much for that clarity.

I will move on to Elena Whitham, who also joins us online.

Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP): Good evening. I declare an interest, in that I am a Humanist Society Scotland member and I am also a Canadian citizen.

My first question is on coercion and safeguarding. In the interests of time, I will join my questions together, so I will just have one question in total. Like the bill, Canadian law seeks to prevent coercion. What measures are in place to ensure that only those who fully meet the criteria have access to MAID? We can keep it to track 1 MAID, as that is the equivalent of the proposed law that is in front of us—we do not have a track 2 option.

The second part of my question is about specialist training. How do we ensure that doctors who provide MAID are adequately trained to assess coercion and to ensure that safeguards are in place? I will start with Dr Green and then go to Dr Coelho.

Dr Green: I will be concise. There is zero evidence—[*Inaudible.*]—the MAID patients. I think that we can all agree that Twitter stories or catchy headlines in *The Herald* or the *Daily Record* are not evidence. I see far more examples of people being coerced out of accessing MAID by their loving family and friends than examples of people being coerced in. In the several hundred cases that I have dealt with, I have seen two cases where I truly thought that there might be an element of coercion happening. In one of them, I was able to satisfy myself that there was no coercion, and the other case I found to be ineligible.

You are asking whether clinicians know how to do their jobs. We certainly do, and we now have training in place to teach about how to look for coercion. That is not just about explicit coercion by angry people or greedy family members—that is the more obvious coercion. We also teach about more subtle forms of coercion. That is about looking at vulnerabilities and looking for marginalisation and how those things might be involved in a patient's decision.

We introduced the training for that a little bit later. My colleague mentioned CAMAP's Canadian MAID curriculum. I will just say that CAMAP is clearly not an advocacy group—we are subject matter experts and we were consulted by Health Canada and asked to make that training program, which is now available. There is a whole section on how to train clinicians to deal with coercion in order to maintain the situation of there being zero evidence of it happening in Canada.

Elena Whitham: Dr Coelho, do you want to come in?

Dr Coelho: I did not get a chance to answer the earlier question, so I will first submit that the coroner has actually made reports on failed MAID cases by IV in Ontario. Cases have gone to the college for that.

Moving on to coercion, we have spoken about not quoting headlines, so I will stick to the evidence. CAMAP has a policy on bringing up MAID, and a lot of clinicians—I am not talking only about MAID providers; I am talking about community providers who might even be trying to be helpful—can repeatedly raise MAID with the same patient. I think that that can be undue influence or can confirm to the patient, if they are feeling hopeless, that their life is not worth living. That is the opposite of autonomy.

In terms of the coroners' reports on coercion that need to be sent out to MAID providers in Ontario because of recurrent cases, lessons have been learned on voluntariness. In May—this point will be in the article that I mentioned in *The New Atlantis* and I think that it was also released by

Maria Cheng—the lessons learned were sent to all the MAID providers in Ontario.

There was a gentleman who set up his wife's provision—and, as a side note, the coroner mentions that that really calls into question the voluntariness of her wanting to have MAID. There are other cases of duo euthanasia in which one partner seems to be wavering, and they have cancelled MAID and then re-set it up. There have also been cases of spouses burning out and doing the MAID co-ordination. All of these things I will send you from the coroner's office.

It is very nice to say that we have no coercion, but we have no robust safeguard to prevent coercion in real time. That is very scary to me. Just as a human and as someone who understands discrimination and the way in which people can treat certain types of people as being less worthy of care, I do not think that there is any evidence that there is not coercion. In fact, I will send you the evidence that there is.

Elena Whitham: Thank you. I have other questions, convener, but in the interests of time, I will pass back to you and other colleagues.

The Convener: Thank you very much. I call Emma Harper.

Emma Harper (South Scotland) (SNP): Good evening to you both, and thank you for being here. I am just going to pick up on issues with regard to the training and education required—and I am speaking not just in terms of training to identify coercion, but training in general. Can you say a little bit about what has been set up in that respect?

One issue that came up last week was that the bill in Scotland just refers to a "registered medical practitioner", which could mean foundation year 2 doctors all the way through to consultants. Can you tell us about your process in Canada with regard to education and training? That question is for Dr Green first, I suppose, or perhaps Dr Coelho.

Dr Green: As I mentioned at the beginning, there were no formal training programmes. It is the opinion of most clinicians that medical and nursing training provides people with the skill set to practise medicine, and that we already use those skills in our everyday practice. We assess capacity and voluntariness in every interaction with every patient multiple times a day; for example, we cannot give medication to a patient who does not understand what it is for or what the alternatives are. There are higher levels when it comes to surgery or whether, say, a patient should start or stop dialysis. We could make a huge list of things in that respect, but assessing capacity and ensuring informed consent are standard practices that all healthcare practitioners are trained in.

It is, of course, always ideal to have extra training in a field that you are going to be spending more time in. As we have mentioned, CAMAP is a national professional organisation founded to support the diversity of professionals who do this work, to educate the healthcare community and to practise the highest of standards. We are the subject matter experts, and we have developed a nationally accessible, bilingual, hybrid, online, in-person MAID training programme that has eight distinct modules that cover the foundations of MAID in Canada; how it came to be; the ethics around it; how to have clinical conversations around MAID while you are having end-of-life conversations; how to do a basic MAID assessment; how to do advanced capacity assessments and assess vulnerability; how to do provision of MAID; how to approach complicated and complex scenarios; and how to deal with mental health issues when they show up in your MAID assessment. It is a very comprehensive programme that had, if I can remember, about 100 different sets of eyes on and stakeholders involved in the content as it was being developed. It has now been rolled out and is available across the country free of charge to any licensed medical professional, medical doctor or nurse practitioner in the country.

We are hoping that that will help standardise the approach to the assessment and delivery of care. Would it have been ideal to have had this in the early days? Yes. Are we glad that it is there now? Yes. Is it required in order to practice MAID? No, it is not. We do think that doctors and nurses have the skills in that respect. However, we do recommend that people take the course.

Emma Harper: Dr Coelho, I think that you wanted to come in, too.

Dr Coelho: Sure. I agree with Dr Green that no formal training is required to provide medical assistance in dying in Canada, that the CAMAP curriculum has come late and that it was waiting for funding—which I am not blaming CAMAP for. The funding came in 2023.

My concern is that it is very nice to say that we all have training, but we have to think about what is required with regard to capacity. One of my good colleagues is the capacity expert at her institution. When I was at McGill University, if I did not know whether a patient had capacity, especially when it came to financial issues, I would send them to her, and she would spend, say, 10 hours doing a capacity assessment. That is not happening with MAID, where I would say the stakes are higher, and that is very concerning to me.

My colleague reviewed the CAMAP curriculum and did not feel that it is adequate given the seriousness of the decision making that is

happening. That is not a knock to anybody; it is just a statement. The same thing applies with MAID in relation to the curriculum for potential future mental illness. In general, Madeline Li, who developed that curriculum, has raised issues with the openness of MAID in relation to psychosocial suffering and things that can be approved. I would not say that we are in a place where we have great education or standardisation.

Emma Harper: Okay—thanks. I will leave it there, convener, as I am conscious of time.

The Convener: Thank you. Brian Whittle is next.

Brian Whittle: I will be brief. If we have time at the end, I will try to come back in with some other questions.

Dr Coelho, you brought up the issue of capacity to make the decision. In relation to people with dementia who may lose capacity towards the end of their life, is there any provision under the assisted dying law in Canada for people to put in place an advance directive for a situation where they lose capacity as their condition deteriorates?

Dr Coelho: Right now, as Dr Green pointed out, most cases are euthanasia, so a date must be set. It can be pushed back if a person has capacity. If there is fear that someone is going to lose capacity, the legislation allows for a waiver of consent. The MAID provider and the patient may enter an agreement that, if the patient loses capacity on the day, after they have had capacity during their two assessments, they can go forward on the prescribed day.

As it turns out, your question is timely, because Quebec announced on 30 October that it is going to go ahead, even though it is against the criminal code, and have MAID by advance request period, meaning that a person who foresees that they might lose their capacity may prescribe in a written document what provision they would want made at a future date. That will be for someone else to enact. The federal Government has just announced that it is going to do a quick consultation, which will end in January, and that it will not go after Quebec for that, so it looks like we are expanding to fuller advance directives. I am not sure whether you want to know my thoughts on that or just where we stand on that.

Brian Whittle: I will happily take any insights that you can give us.

Dr Coelho: Okay. I take care of my father with dementia. I also did home care for many years where I took care of people with dementia. Our system is failing people with dementia in terms of services. I think that people have a lot of fear of cognitive impairment in general because of the way that our society is structured and how we see

loss of cognition as loss of dignity, and because people may not understand that their future self would be totally happy with dementia, as many of the patients that I cared for were.

The question is whether a person can, as their younger self, actually predict when they would rather not be living. Most studies show that, if they rate their quality of life, people with disabilities who have had time to adjust and people with dementia will rate it very highly, whereas an able-bodied person who rates what their quality of life would be in those circumstances will perceive it as very low. That is the problem and, for me, the fear about advance directives—that people will enter an agreement that will be enacted later by a third party when, actually, they may not be unhappy at that time.

That also creates a lot of uncertainty for the providers and the family. When do we enact it? There are a lot of questions. A lot of MAID providers have spoken about that, even in Quebec. Very well-respected MAID providers are very concerned about the expansion.

Brian Whittle: I see Dr Green nodding in agreement.

Dr Green: A robust discussion on the subject needs to happen in Canada, and I think that will be happening, especially with Quebec's advancement. The way that Quebec came to this was via a completely different system, but I am sure that you do not want to get into the weeds of that. We know that over 80 per cent of Canadians want advance requests, so they are something that we will have to grapple with. I think that it will be years before we see them in the rest of Canada, and we will be looking carefully at what Quebec has done and what has and has not worked.

This is the next robust discussion to have in Canada. There are certainly mixed feelings about it, and I look forward to the discussion.

Joe FitzPatrick (Dundee City West) (SNP): An argument that is sometimes made in support of assisted dying is that, without a lawful alternative, people might choose to die by suicide. Indeed, I think that Dr Coelho touched on that. Have you seen a difference in that respect? Has there been a reduction in folk using suicide as a way of ending their lives now that there is a legal alternative?

As you mentioned the point, Dr Coelho, do you want to answer that question first?

18:00

Dr Coelho: The Canadian Association for Suicide Prevention has been very vocal on that. There are concerns that assisted suicide is

basically usurping the previous role of suicide prevention, especially outside the end-of-life context, and that people who traditionally would, with care, recover from a suicide attempt and who would go on to heal and enjoy their lives are instead having their lives ended at their worst. Again, I encourage you to read the case reports that are included in the coroners' reports.

As for evidence from overseas, David Jones, who I think is in the United Kingdom, has written extensively on the subject, and I can send you his evidence. I initially heard an argument that, if we had MAID, we would reduce bridge jumping and people using guns, and that MAID would be better for people who would commit suicide anyway.

My understanding is that the data in Europe does not show a reduction in suicides. I am very concerned that, instead of helping people to have hope and look for options to live, as the Canadian Human Rights Commission has stated twice now, we are instead—through a lack of support or care—ushering them to a premature and wrongful death.

Dr Green: I will make two brief points. First, it is important to clarify the terminology. Suicide prevention organisations around the world have themselves said that conflating suicide and assisted dying is not just unhelpful or damaging; as the organisation in Australia has said,

"it is inappropriate and insensitive to characterise a wish for an assisted death as being suicidal".

You will no doubt hear from witnesses who use terminology such as doctors "killing" people or who talk about "assisted suicide", but those are not terms that we use in Canada, for obvious inflammatory reasons.

In direct answer to the question, however—and if you have not already seen the graph—I would point out that, in Canada, rates of suicide were slowly increasing until 2015. Since then, and particularly as MAID numbers have climbed—as we have alluded to, they have done so substantially since that time—suicide rates have in turn started to fall dramatically. Indeed, they are currently at the lowest rates that they have been in my lifetime and are possibly the lowest ever recorded. I have a chart for that, if you have not already seen it.

Brian Whittle: It has been very helpful to hear two different sides of the argument. Thank you both for that.

One thing that has just been raised is coercion, as well as what might almost be coercion to prevent people taking part in MAID. Has there been any legal response, or have there been any legal cases after a patient has accessed MAID? Are there any figures on that?

Dr Green: We do not have national figures on that, as that is not something that we record or which we are required to report. We do not have national numbers.

There have been a couple of court cases. Offhand, I can think of one, from Nova Scotia, in which a man applied for assisted dying, and his wife very much did not want him to do so. She could not convince him not to; he wanted to go forward with it, and was found eligible. She went to court to try and stop him, and the court decision was quite clear on the reasons why she was not eligible to do so. She did not have standing in that respect. There was another case in Alberta, and I feel like there is a third case, but I cannot think of it right now.

We have snippets, or little pieces of evidence, that that is happening, and people are trying to go to the courts to prevent such things, but we do not have national numbers on how often that happens. I can give you only anecdotal evidence: I have assessed somewhere between 400 and 500 patients for assisted dying, and I have seen very few cases where I was worried about coercion. I think that that is something that we can assess quite well. I have seen probably five to 10 times as many people convinced that they should not to go forward, even when found eligible—having been asked, for the sake of their family and friends, to stick around longer.

Brian Whittle: Dr Coelho, do you have anything to add?

Dr Coelho: Yes, a few things. First, I want to clarify that, in response to the previous question, I was talking about MAID outside the end-of-life context.

On this question and in relation to family members, I would point out that we do not live in isolation. There is a false construct of autonomy. In the case of a family member who is distressed that a person might die, it might be that they are coercing them not to die; it might also be that there are concerns that the MAID provider has overstepped their powers or is abusing the legislation.

In the Nova Scotia case, if I remember correctly, the gentleman had seven assessments before he was approved, which shows that he could doctor-shop until he found two favourable assessments. With the case in Alberta—the lady with autism who was covered in the news—there are also concerns. There is a very concerned father who has been vilified by the MAID community as he tries to prevent what he considers to be the wrongful death of his daughter.

The third case—the Dr Green one—is happening right now. It involves a woman with mental illness; she has akathisia, so she has side

effects from her medications. Her doctors in Alberta did not think that she qualified, but she contacted, via video conference, a doctor in BC, who approved her through video assessments. She flew to BC to get MAID; however, the family and friends got an injunction from a judge that same day, as it did not look as though there had been due process—the second assessor was set up by the first assessor, even though they are supposed to be independent. There was a question whether such things represented an irreversible decline of capability or something applying to akathisia that had not had proper trials and treatments.

There has to be an understanding that that is a very complicated discussion. Families love their family members—indeed, I would hope so. Sometimes, when families are trying to get their loved one not to die, it is because they see hope. Perhaps a practitioner cannot see that, because they do not know them as well.

Emma Harper: I have just had a thought that takes me back to the participating physicians. Is there any data on how long these physicians have been practising? In the proposed legislation, doctors whom we would consider as being junior could be making the choice whether to assist somebody at the end of their life. I am thinking, too, about medical practitioners such as nurses, pharmacists and doctors who might feel coerced into providing support when they might want to conscientiously object. Do you have data on that?

Dr Green: We do not have numbers for people who conscientiously object, but we definitely have an explicit line in our federal legislation allowing for and respecting conscientious objection, which goes for pharmacists, junior doctors, older doctors and nurses. Anybody at all in healthcare can choose not to participate in this kind of care, and that is absolutely respected across the country.

There is no minimum amount of time that you need to have been practising in order to qualify to do this work. The legislation set the bar at people licensed to practise through either medical licensing or nurse practitioner licensing. Provinces can set their own standards if they wish, but that is the federal standard.

In respect of your last question, I encourage anybody interested in the Sorensen case in Nova Scotia to read the response to that, which makes things clear. We should also not presume that anybody knows anything about the other cases, given that we are only hearing one side from the newspapers. I will not presume to tell you the details of the cases, even though I might know some of them.

Dr Coelho: As Dr Green has said, our law has a direct legislative requirement that no doctor is

forced to participate or assist, but that has been taken mostly to relate to the actual provision. There was a press release from a group of doctors who, although worried about bullying, came forward to say that they feel pressured in hospices to be the most responsible provider. Ellen Warner, an oncologist at Sunnybrook hospital in Toronto, testified about on-going bullying, because she is a conscientious objector; she is an Orthodox Jew, and someone stood up and said to her, “You know, people like you do not belong in this hospital.”

We have effective referral in Ontario, which means that, even if you are a conscientious objector, you still have to make a referral. In principle, that sounds great for a patient, but the way in which the model practice standard and the document are written, MAID providers still have a professional consideration, even if they conscientiously object because of psychosocial suffering.

Indeed, such a situation is highlighted in one of the CAMAP training videos that has been released. A bioethicist tells a doctor—who is a MAID provider but is not comfortable with MAID for psychosocial suffering—“Well then, you will have to make a referral and hopefully the next person will do it.” There are problems with mandating participation when there are other systems might actually protect patients better.

Dr Green: There is no mandated participation anywhere.

The Convener: We have a final question for both of you, if that is okay. I appreciate that you have stayed a bit longer than you had initially agreed to.

Paul Sweeney: I thank both Dr Coelho and Dr Green for their persistence and patience with us as we go through these complex issues.

I want to ask about cases that have come up from constituents. This issue is often discussed in the context of end-of-life care a matter of hours out from death; it might be when people have experienced progression of, say, pancreatic or throat cancer, their quality of life has deteriorated significantly and they are verging on terminal agitation, with sedation considered. They might want the comfort of having the option to end their life at that stage, anticipating that deterioration will follow that course.

Do you have experience of the dynamic playing out in that way in Canada, with people fearing progression of their condition and what that will mean for their quality of life? They might want to have that option, with prior approval, to give themselves comfort as they face a terminal illness with a pretty bleak prognosis. There might come a point later when, once a certain threshold has

been passed, they can trigger the end of their life on their own terms. Is that a common characteristic of how this plays out?

Dr Green: I really appreciate the question. It is easy for us to sit here and talk about the effect on doctors, laws, ethics and different things, but this type of care is really about patients. It is important that the committee understands why you are even considering assisted dying; it should be patient centred and about patient suffering. In Canada, we focus more on suffering than on end of life. As I have said, I really appreciate the question.

It is quite common, especially at this stage in Canada, for people to come to us earlier in their course of illness. Originally, they came quite late and in the situation that you have described, perhaps literally at the very end, which is probably too late for MAID. The example that you gave in which someone is literally hours or perhaps a day away from terminal delirium is not an appropriate case for MAID. Instead, it is an appropriate case for good palliative care, which is how that would play out in Canada.

Getting MAID in place involves a rigorous process. I see lots of patients who come to me earlier on. They tell me what is important to them, what is meaningful in their life, what still brings them joy, what they have lost, what they want and why they want it. After that rigorous process, there are times when I can tell a patient that, in fact, they are eligible for MAID, and I see a transformation. It is physical, and I see it almost every single time: the patient relaxes. They no doubt express their gratitude for the option and mere possibility of an assisted death, but their level of suffering literally goes down.

I expect—although I do not have data for it—that they live longer, because they know that they have this trump card in their back pocket. I see them immediately shift from focusing on their fear of how they will die. Let us face it: that is why they have come to me. They are scared of their decline and fearful of what their death will be like. Once they know that they have this option, they immediately start focusing on how they will live the rest of the time that they have left.

In the end, a significant portion of patients do not choose to have an assisted death, simply because their suffering goes down once they have that as a possibility. However, a larger majority goes ahead, sets a date and proceeds with MAID. We see the therapeutic value in having open and honest conversations with patients about true end-of-life options that might or might not include palliative care, MAID or a whole bunch of other resources. They want the possibility—that is therapeutic in and of itself. That is what we see.

Paul Sweeney: Dr Coelho, do you have a perspective on that late-stage option for people who want to retain their sovereignty?

Dr Coelho: Consistent with Canada, most international evidence shows that people choose MAID earlier and that they choose it out of fear of being a burden—that is highly cited, internationally. If you look at the Health Canada reports, you will see that fear of being a burden and loneliness are high up among the top five reasons for people choosing MAID.

I understand the scenario that you have painted, but if you look at the first 100 cases of MAID deaths that were approved in Ontario—through track 1, before the expansion—you will see that reasons given for choosing MAID included anorexia and grieving. What is playing out a lot in reality is not the sort of autonomous set-up that I think that you are thinking of.

I just want to say to Dr Green that I understand that her practice is good—I have heard that from other people—but I think that other MAID practitioners do not necessarily have the same practice standards or patterns that she has. That means that a lot of other people are being approved for MAID and are, as I consider it, getting a wrongful and premature death when they should have got care instead.

The Convener: I thank you both for joining us today. You have certainly given the committee a lot of food for thought. I appreciate the time that you have given, and I am sure that your evidence will help us in our consideration of the bill.

Dr Coelho: Thanks for having us.

Dr Green: Thanks for having us.

The Convener: At our next meeting, which is tomorrow, Tuesday 12 November, we will continue to take oral evidence as part of the committee's stage 1 scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill.

That concludes the public part of today's meeting.

18:14

Meeting continued in private until 18:15.

This is a draft *Official Report* and is subject to correction between publication and archiving, which will take place no later than 35 working days after the date of the meeting. The most up-to-date version is available here:
<https://www.parliament.scot/chamber-and-committees/official-report>

Members and other meeting participants who wish to suggest corrections to their contributions should contact the Official Report.

Official Report
Room T2.20
Scottish Parliament
Edinburgh
EH99 1SP

Email: official.report@parliament.scot
Telephone: 0131 348 5447

The deadline for corrections to this edition is:

Wednesday 11 December 2024

Published in Edinburgh by the Scottish Parliamentary Corporate Body, the Scottish Parliament, Edinburgh, EH99 1SP

All documents are available on
the Scottish Parliament website at:

www.parliament.scot

Information on non-endorsed print suppliers
is available here:

www.parliament.scot/documents

For information on the Scottish Parliament contact
Public Information on:

Telephone: 0131 348 5000

Textphone: 0800 092 7100

Email: sp.info@parliament.scot



The Scottish Parliament
Pàrlamaid na h-Alba