Transcript – MAID Information Evening

St John’s Church Parish Hall - Tuesday, June 9, 2026

Rev. Gary van der Meer

Good evening and welcome. Welcome to our questioning evening about medical assistance in dying. We want to take into account that some of you are excited about what we're going to learn, while some of you are hesitant. We are not here to persuade you in any direction. We are here to respect where each other is coming from and to give enough information so you have some insight about medical assistance in dying. When we come to the time for questions, I would ask you to frame the question in “I language” rather than “we language” (which presumes that everyone thinks the same as you). Our purpose is to create a setting where questions are welcome.

I would like to welcome our special guests.

- Dr. Justine Amaro is an Emergency Medicine and MAID physician at the Ottawa Hospital, and Assistant Professor in the Faculty of Medicine at the University of Ottawa. We have been friends for over 5 years, and it's great to have Dr. Amiro with us.
- Dr. James Downar is the head and professor of the Division of Palliative Care in the Department of Medicine at the University of Ottawa, Clinical Research Chair in Palliative and End of Life Care for the Faculty of Medicine at the University of Ottawa, Staff Physician, Department of Critical Care at the Ottawa Hospital, and Investigator for the Bruyere Research Institute. Our connection is through Compassionate Ottawa, and I'm grateful to Monica Patton, who connected Dr Downar to St John’s.

I would also like to extend a welcome to my clergy colleague, the Reverend Al Budzin and his wife Julie; to Leigh Anne Williams, who writes for our Anglican Diocese newspaper; and to our friends from First Baptist Church. You may be aware that our four neighborhood churches come together as the Four Amigos Churches. We try to share, help and support each other. I will be asking the Reverend Dr. John Perkin to do a closing prayer at the conclusion of our evening. Welcome to our St. John's community and any friends that you brought along. My name is Gary van der Meer, and I'm the rector of the parish.

This evening’s session will cover: An overview of MAID, some of its history and how it came into the medical system, who is using it, any ethical concerns or legal constraints.

Practically speaking, what happens with the procedure of MAID? Who qualifies and how is MAID accessed.

Dr. Justine Amaro

Thanks, Gary. It's a pleasure to be with everyone here today and with Dr. Downar. As Gary said, we've been friends for about five years and I'm a physician at the emergency department at the Ottawa Hospital and have been doing MAID for about seven years now. I see a lot of MAID patients in the Champlain region that fall into both tracks of MAID. I welcome the opportunity tonight to be able to just hear questions and welcome anything really that comes up. We'll talk a little bit about where MAID has come from, where we started thinking about it and how it's evolved and what it looks like locally.

Dr. James Downar

Thank you very much. You've already heard my introduction. I first became involved in medical assistance in dying some years ago before it was legal, mostly in an advocacy capacity. I had worked in medicine for many years and really don't think I had a particularly strong opinion on it, but felt that it's something that should be legal. But a mentor of mine had a particularly poor experience as he died. And he was a very well-known physician, Dr. Don Lowe. Some of you may know him. I worked in his lab, and he made an impassioned plea for legalization before he died and recorded it. And that's what sort of prompted me to become a bit more vocal about my views. I was involved a lot in the provision of MAID early on after it was legalized. in the 2016 to 2019, 2020 period. I've become less involved in assisted dying. I was originally living in Toronto, don't hate me. But I moved to Ottawa in 2018 with my family to take up the role here. And I've been a little less involved in the provision of MAID, but more involved in doing research and data collection. So I'm going to start by perhaps talking a little bit about a shortened version of the background of how we got here legally. Father Gary begged me to make a very long PowerPoint presentation full of data. And I said no. I said no. I'm not doing it no matter how much you beg me. So I'm just going to try to give a brief version, but if you want to ask about any details, I'm happy to speak to some of the details. The history of assisted dying in Canada is quite long, obviously, in terms of the legal process to how we got here. But the first, I think, very serious effort to legalize assisted dying was the case of Sue Rodriguez. Many of you may remember she was a woman with amyotrophic lateral sclerosis, also known as ALS or Lou Gehrig's disease. She went to court to try to get the right to have a physician help to end her life. She was not successful. She lost by one vote at the Supreme Court of Canada in 1993. There were a number of legislative attempts following that, something like 22, I read that number somewhere. None of these were successful. But another case came forward in the early 2010s. a case involving another woman with ALS and a woman with spinal stenosis.

This is known as the Carter case. And they won their case in BC Supreme Court, BC Court of Appeal, and ultimately the Supreme Court of Canada. This legalized assisted dying for people with what they call a grievous and irremediable medical condition. They define that as serious and incurable, advanced state of irreversible decline in capability, and somebody who's experiencing intolerable suffering or suffering that was intolerable to them. Justine's going to get into some more of the details around that, so I'm not going to steal her thunder. That was the court's decision. And so what the court can do is can take away a law, can strike down a part of the law. The court cannot write a law, so the Parliament had to respond by passing a bill. Bill C-14 was what came out. They essentially copied what the Supreme Court had done and said these three criteria, they added a fourth. that was called reasonably foreseeable death. So the person had to be at a point where they had a natural death that was reasonably foreseeable. It was a sort of a vague criterion meant to limit it to people who were nearing the end of their life. That was not part of the original Carter decision. It was challenged very early in a court case in Quebec called the Truchon case. That was two individuals with disabilities but not terminal conditions who wanted the right to receive assisted dying. They were successful in that court case. It was not appealed, and both the government of Quebec and the government of Canada decided to change the law accordingly. So now we have made available for people with a reasonably foreseeable natural death track one, and people without a reasonably foreseeable natural death, that's sometimes known as track 2. That's where the law sits at the moment. Quebec has gone one additional step further, where they passed a bill allowing made by advanced requests for people who have a condition where they know they will lose their ability to make decisions in the future, but they haven't yet lost that ability. So you can write a very detailed set of instructions that would be followed with instructions to a physician and a close one. I'm not going to get into the details of that bill because of course it doesn't apply on this side of the river. But that's the only exception to the current legal situation in Canada. We have a lot of data about the practice of MAID in Canada, and there's been a lot of attention paid. I will try to give you a very brief summary of some of the data that we have. But so in the last year for which we have data, so we get a report for every year, and it's delayed by about 10 or 11 months, which is normal when you're doing big data reports. I imagine many of you at some point worked for the government So I'm going to guess that a 10, 11 month delay for a report is not going to be something out of your experience. It's fairly normal for the type of research we do. This report includes the numbers of people getting made. In 2024, it was about 16,000, almost 16,500 people. That's about 5% of all deaths in Canada. Most of those were the track one deaths that we talk about. The numbers are different in every province. So, you have a very high number, for example, in Quebec and in British Columbia, closer to 8%. In Ontario, it's sort of in the 4% range. Manitoba is closer to 1 to 2%. So you see a bit of a range there. And

even within provinces, you will see dramatic differences. Vancouver versus Vancouver Island. Vancouver Island, it's well over 10% now. Anyway. So you will see a lot of variability across the country. We know a lot about the individuals who are getting MAiD, who they are and what they have. The large majority of people who are receiving MAiD in Canada have either metastatic cancer and advanced cancer, or they have ALS. And those two conditions together account for something between 70 and 80% of cases. The remainder would be a mix of heart disease, lung disease, etc. So you're, again, you are much, the most, the condition for where people are most likely to get assisted dying is ALS. After that it would be cancer, and after that it would be everything else. And the differences between those are like sixfold differences. They're very, very big differences. We have a lot of data about the demographics of people who are receiving MAID. So it is very predominantly white Caucasian individuals, 96% white. We have a variety of metrics that we can collect that measure different forms of marginalization. So we have income. We know that people who receive MAID are more likely to come from high-income neighborhoods and less likely to come from low-income neighborhoods than people who receive, than people who die naturally. We have a number of metrics that we use that capture things like education, housing, whether you're in receipt of government benefits, et cetera. For all of these metrics that we use to measure marginalization, they all show that Canadians who receive MAID are more likely to come from privileged neighborhoods and less likely to come from less privileged neighborhoods. We know that people who receive MAID are more likely to come from urban areas and tend to have better, closer access to hospital care. than people who are further away. It's very hard to measure access objectively, but that's a metric that we use sometimes. And there's a number, again, we can go on and on about other demographics of individuals who receive MAID. We also know about Indigenous peoples, and we know that Indigenous people are about 1/3 as likely to get MAID as non-Indigenous Canadians at the end of life. So whereas about 5% of Canadians who die naturally are as Indigenous, it's only about 1%, 1.5% of people who get MAID who identify as Indigenous. So those are some of the numbers, and I can answer other numbers if you have them. One of the things I said I would do and forgot to do was to sort of preface all of this by saying, I'm going to give you some numbers. Now, one of the things that happens in this debate, there's sort of two fallacies in the debate. One of them is to say that it's what we call the naturalistic fallacy, for those of you who are philosophy fans. The naturalistic fallacy is to say that because of a piece of data, we will infer a moral position. So if I tell you that MAID recipients tend to be more privileged, they have higher involvement of palliative care, they come from wealthier neighborhoods, et cetera, That's a data statement of fact. That doesn't mean that MAID is a good thing. Whether it's a good thing or a bad thing is a moral question. And that's a question that operates on a different level than the data question. So the naturalistic fallacy is to look at data and then draw a moralistic

conclusion, which is wrong. On the flip side, the moralistic fallacy is the inverse, where we decide that we think something's good, therefore we're only prepared to acknowledge data that fits with our position, whether that's good or bad. And we have to be very careful to understand that it's okay for us to accept data for what it is, even if that's not the reason we support or oppose assisted dying. So I want to say that because I just want to be clear that it's actually possible for multiple opinions to coexist and for everybody to be right, if we can put it that way.

Dr. Justine Amaro

I'm going to start out just by talking a little bit about our Champlain Health Region here and what our team looks like. We have a primary team that works out of the Ottawa Hospital. There are about 17 of us that do a lot of MAID assessments and provisions. The Monfort and the Queensway and some of the community hospitals have some providers also, and there are also some family physicians in the community who will provide or assess for their own patients. I get often asked, like, what's the process? How long is it going to take? And is this something that's going to take years? People are concerned, understandably, how early should I embark upon this journey? And it's not a long process. The process involves essentially getting a referral from your physician or any physician. You cannot self-refer to the MAID program in the Champlain region currently. So any physician can refer you and then an intake will be done by one of the nurses, usually within a matter of weeks. and then the cases are triaged according to their acuity. In other words, when we see a referral from an inpatient who is perhaps suffering very severely nearing the end of life, having palliative care with very intolerable suffering, those cases will get triaged to be seen more quickly than perhaps someone with a newer diagnosis of a cancer that may well still be eligible, but their death may still be years away. So they don't need to be seen quite as quickly. So the nurses do do an intake process of triage. And then based upon that, they will send out a first assessor. And at that point, one of us, we usually do these as home visits, which is a real joy as a physician, especially as an emergency physician, where normally it's quick paced. And if any of you have had the fortune or misfortune of coming to the emergency department in the last five years, you know the wait times are long. So it's a real joy to be able to go and actually do home visits and meet people in their space and be welcomed there. It also tells me volumes about each person that I'm meeting. And then we undergo the MAID assessment process together. I often am asked, is this going to be a long appointment, a short appointment? And really the answer rests with the patient. Some patients are very quick and lickety split and they want to just get the questions answered and go through it in 20, 25 minutes and we're done. And sometimes I have the pleasure of sitting over a cup of tea for an hour or two. So it's really quite variable. And sometimes it depends a lot on the complexity of the case also. So that's the process part. Following that,

most times at the time of assessment, we can tell you as the first assessor whether we do or don't find you eligible for MAID according to the current legal criteria. Sometimes we can't tell you on the spot if it's a really complicated case. Sometimes we need to go back and review more things in the chart, consult with other physicians, other healthcare professionals. But most of the time we can usually say, yes, I find you eligible, which then starts the process for the nurse team to reach out to a second physician. Nurse practitioners in Ontario are also allowed to assess and provide for MAID, but in our group within the Ottawa Hospital in the Champlain region, we are all physicians, so it's a physician team only. but our intake team are nurses. And then second physician's going to go, they're going to do the, I say, they're going to have the exact same conversation with you and ask you all the same questions because you have to do this twice, answer the same questions twice. And as I say when I arrive, although I've reviewed your chart and I know all the medical stuff, This is my opportunity really to get to know you and to hear your story and to understand your journey and your illness experience and your suffering because really the eligibility doesn't come just from the chart, but it comes from the human who I'm speaking to. So we go through two assessments and then if one is found eligible, we report that back to our team. And at that point, if you were under track one, which I'll elaborate a little bit more on, then you are eligible for MAID and you can choose to go ahead at any time. You are never obliged to go ahead. In fact, many patients that we see never do go ahead, actually. but the relief that they feel in being approved and knowing that, okay, it's an option for me, I'm not going to have to suffer at the end of life when I feel like it's too much, it's there. Even that relief is therapeutic. And so many of my patients, I don't see them again. So that's sort of what the eligibility looks like. I do want to speak briefly about track 1 and track 2 because it does actually change the process a little bit, which is what I wanted to get into. So track 1, as Dr. Downar already referred to, these are patients who have a reasonably foreseeable natural death. It's a vague term. it's kind of intentionally vague. As a MAID assessor and provider, sometimes it's frustrating that it's vague, but sometimes it's liberating that it's vague. So it can either go either way. But essentially what that means is that we feel, as your physician who's assessing you, that you have an illness that makes your death reasonably foreseeable to us sometime in the future. There is no timeline on this. So unlike what has recently, unfortunately, come forward in Alberta, or what is the case currently in the few states in the United States that allow MAID, this is not a defined timeline. This is not three months, it's not six months, it's not a year. In Alberta, it has recently been changed to one year. But everywhere else in Canada, there is not a timeline for reasonably foreseeable natural death. So it does not mean that you are imminently dying, imminently receiving palliative care and are in the final stages. Reasonably foreseeable natural death for a patient with Alzheimer's disease could mean that they may still live another eight years. So timeline can be quite variable as

to what that actually means for a reasonably foreseeable natural death. The difference in the process is that if you are a track one patient, in other words, you have an illness which we deem to have a reasonably foreseeable natural death, which is usually cancer, neurodegenerative like ALS, sometimes Parkinson's, sometimes primary progressive multiple sclerosis, supranuclear palsy, there are a number of those. or any of the other, the lung and heart diseases, some severe heart conditions, interstitial lung disease, and then there's a sort of bag of a few other conditions along the way that can all fall under track 1. Whereas track 2 are patients who do not have a reasonably foreseeable natural death. And this encompasses a very wide group of illnesses. This can really be at any age. You do have to be over the age of 18 to qualify for MAID. MAID is not available or legal for minors. But aside from that, the youngest patient I've seen who has been approved for MAID was 24 years old. And that was not for cancer. That was a non-reasonably foreseeable natural death. So it really spans from the young until the old. But these cases have other requirements. So essentially the first thing when you get your assessment is we decide are you track 1 or are you track 2? And then we need to go through the criteria to even see are you eligible, which again will address the eligibility criteria. But for track 2 patients, if you do meet all of the criteria to be eligible for MAID, but we decide that your death is not reasonably foreseeable, then there is a minimum 90 day waiting slash assessment period from the date that your chart is first opened. For our team, what that actually looks like is the date of your first assessment. Legally, it's technically the day your chart is first reviewed by a physician. So within that 90 days, the patient will be required to see a physician who has expertise within which the area of that patient's suffering lies. So for example, if it's a patient with, for example, chronic pain, again, nothing that is going to cause their death to be foreseeable, but they have severe unremitting chronic pain, they will be required to see a pain specialist. And the requirement is that the pain specialist will offer the patient all of the therapeutic options that are available to relieve the patient's suffering. The patient does not have to agree to any of these treatments. It's perfectly fine for them to say, nope, that's not within my goals of care. I don't want that injection. I don't want that procedure. I don't want that surgery. They can refuse. But from an assessment perspective, they have to demonstrate that they have given due consideration to what was offered to them. So they have to understand what was offered. They have to attend the appointment and be made aware. And then I have to have another meeting with them to say, hey, the pain physician offered you these options. What did you think about this option? What did you think about that option? And if they say, Dr. Marrow, I don't want any more procedures. And they can explain a rationale and they've given due consideration, then we're done. Now this may be more than one specialist. For example, sometimes patients in track 2 may require to see a specialist in other areas. It's quite common there may be psychiatric comorbidities. So currently in Canada, you've probably heard in the

news a lot of the controversy about mental illness in MAID. Currently MAID in Canada is not available to people whose sole underlying medical condition is a mental illness. What that means is If you have another illness that makes you eligible for MAID, you absolutely can have concomitant mental illness. It is okay. Schizophrenia, depression, anxiety, any of the mental illnesses, you can have them and still be eligible for MAID. But they cannot be the sole underlying medical condition that would allow you to have MAID eligibility. So in track 2 patients, It's not uncommon that some of the suffering, particularly for patients who have these complex diseases, who may be younger, may or may not be younger, but suffering intolerably, that there may be psychiatric component that may be contributing to their suffering or that may come in as part of their illness. You know, oftentimes to sort that out can be tricky too. So the process then for track 2 is that within that 90 days at minimum, sometimes it takes longer because it's a process and the patient needs to be able to have time to engage in the process, meet with the specialists, take everything under advisement. They may try some treatments, they may not try some treatments, but a minimum of 90 days must pass until they can be found eligible and can have a procedure. And then they will have a second assessment. A second physician will come in. Usually, whichever of us has seen the patient first will have arranged for most of the referrals and assessments. Occasionally, a second assessor may come in and say, I think this patient should also see X, Y, or Z physician. Doesn't happen often, but it's possible. And then once the patient has seen all of the specialists that have expertise within which the area of their suffering lies, they can be found eligible. And at that point, there is no delay to MAID. That's what track 1 versus track 2 looks like. There's one other difference about track 1 and track 2 I want to talk about a little bit later, which is called the waiver of final consent, which is often a very hot topic, which we will get to. But I just want to quickly again review the things that Dr. Downer mentioned for the assessment of what are the criteria. So aside from being over the age of 18, having an OHIP card, you must have a grievous and irremediable medical condition. So what is that? So that is a serious or incurable illness, disease, or disability that causes intolerable suffering and that has placed you in an advanced state of irreversible decline in capability. So I'll speak to the suffering first. The suffering is determined by the patient. The suffering is not determined by me as the physician. I'm going to hear the story. The patient is going to tell me they're suffering. And what one person finds to be intolerable suffering may be very different than what another person may find as tolerable or intolerable or what I may find. That doesn't matter. What matters is that the patient in front of me is suffering intolerably. So that's the intolerable suffering piece. The illness, disability, incurability, that part is essentially present for the patient. It's in the chart. It's something you do discuss in terms of their disease trajectory. But the next piece is the advanced state of irreversible decline in capability. So the wording kind of implies that perhaps you're lying on your deathbed in your final days and you're receiving

palliative care and you're very much at the final stage. And that is not what it needs to mean. What it actually means is that compared to who you were and what your level of function was before you had this illness, you are now in an advanced state of irreversible decline in capability. For an interesting example, if I were assessing someone who's normally an ultra marathon runner who can run 100 kilometers a couple times a week, and now all they can do is run 1 kilometer around the block. That's an advanced state of irreversible decline in capability for that patient. Now you may say, well, but lots of the population can't run 1 kilometer around the block and that's okay, but that's not an advanced state of decline in capability for that patient. The decline in capability piece is something that the clinician needs to interpret within the context of the patient, who they are, what their baseline level of function is, and where they are in their trajectory. So those criteria don't change whether you're in track one or track 2. You must meet those criteria. Intolerable suffering as determined by the patient, grievous any remediable medical condition, advanced state of irreversible decline in capability. Except in Quebec, where they do now have advanced directives, we do not have advanced directives anywhere else in Canada right now. So that means You cannot get MAID set up in advance for in case you have X, Y, or Z condition happen to you, in case you have a stroke, in case you develop dementia, in case you. It's coming, but it's not there yet in Ontario. The last piece about MAID eligibility and assessment that's a little bit nuanced is about something called a waiver of final consent. The thing about consenting to MAID is that the only person that can consent to MAID is the person who is applying for it. You cannot consent to MAID on anyone else's behalf. It doesn't matter if you're their power of attorney, you cannot consent on their behalf. When a person applies for MAID, is assessed for MAID, and is being provided with MAID, that patient must have the capacity to understand and consent to MAID. Capacity is specific to any given task. For example, a patient may have the capacity to say, yes, I would like MAID, but they may not have the capacity any longer to go to the bank and do complex financial transactions. That's okay. Capacity is task specific. So they have to have capacity to understand MAID. I'm often asked what is capacity? And I will say capacity can be tricky to assess. And there are many formal capacity assessments. Some of us may have undergone them or witnessed them in our loved ones from time to time. Some of our psychiatric colleagues will do capacity assessments or psychologists. But really, essentially what capacity means for MAID, because for most of us we're not usually sending patients for capacity assessments, is the patient needs to, number one, understand what is MAID and what are they asking for. They have to understand they're asking for an assisted death and they have to understand the conditions within which they would want that to happen. Number 2, they have to understand the alternatives to MAID. They have to understand that MAID is not their only option. So they must, as part of this process, be engaged in a discussion about palliative care. They don't have to choose to

have palliative care, but most of the patients I meet when I discuss palliative care with them, now some of them are already in palliative care, but there's a general misperception that palliative care means you're dying and you're in your final stages. There's often, almost always, a long discussion about the fact that palliative care is a spectrum. And it is an expertise in medicine where you can be provided with care to help to optimize your symptoms, optimize and improve your quality of life throughout the trajectory of your disease. And it can involve many things. It could involve medications. It could involve personal support workers. It could involve things like as you become more sick, you could require palliative sedation if you're more toward the end stage. Even chemotherapy and radiation can be part of palliative care. It's a wide scope. But part of MAID eligibility is you must be made aware that palliative care exists and you have to demonstrate that you understand that and you can weigh it out. Because MAID, again, in eligibility and capacity means number one, understanding, but also appreciation. You have to really be able to appreciate and you have to demonstrate in our assessment together that there is the ability to have rational manipulation of information. We have to be able to have a meaningful conversation about it. If it doesn't make sense, if the person can't explain to me why, because usually my opening question is after when did you start thinking about MAID is why MAID? Why are you interested in MAID? And if a person can't explain that in some way, then one starts to be concerned about could there be capacity issues. That said, we always come in with the assumption that a patient has capacity. So capacity is important. So currently in Canada, on the day of the procedure, you must have the capacity to give consent. That doesn't mean that we're going to have a long discussion, we're not going to do a formal capacity assessment, there will be no skill testing questions. But if on the day of the procedure I arrive and say, would you still like to go ahead today, and the patient is unexpectedly confused, delirious, they don't know why I'm there, they don't understand what's happening, we can't go ahead. The caveat to that, however, is that we did have a change in the law which brought in something called a waiver of final consent. And I get a lot of questions about the waiver of final consent. And essentially what this is, in cases where we anticipate that there is a risk that the patient will for some reason lose capacity. It doesn't mean they will for sure, but there is a risk that they could lose capacity, and we feel that is a real risk. then we can discuss what's called a waiver, which is kind of like an agreement between the physician and the patient, the physician who will be providing MAID, to say, if on the day of your procedure you've lost capacity, you've required so much medicine perhaps that you're not clear in your mind or your disease has progressed or you've become too sick, you still want me to go ahead. And so that is a five-page document. We go through that. We discuss all of the elements to understand under what conditions the patient would want us to go ahead. We make sure family members or loved ones are involved because we're not going to have as physicians any way of knowing that a

patient has lost capacity unless we're caring for them in the hospital. And if the patient loses capacity, in that case, the loved one can call our team and say, hey, such and such has lost capacity. They're suffering intolerably. We know these are the conditions within which they would have wanted MAID, and then we can go ahead and provide MAID. Couple things about the waiver. Even with a waiver, it is not a guarantee that anyone can get MAID because If the patient in any way demonstrates any sign of refusal, they say no, they say stop, they push us away. Even if it is in a state of confusion, we must stop. We cannot go ahead. And so it's an important part of the discussion to remind patients that ideally when you are choosing to go ahead with MAID, you go ahead while you still have capacity because if that does happen, we have to stop. And if it's with a waiver, we're done. We can't come back. We can't try again. We can't ask later. We're finished. Whereas if you have capacity, you always have the right to change your mind. And if I come and you say, Dr. Mera, I'm actually feeling pretty good today. I don't think I do want MAiD yet. Can we put this off? 100%. No problem. No one's going to be upset with you. We can put it off till any future date if capacity is maintained. But once capacity is lost, if we're going ahead with a waiver and capacity is lost, the patient says no or stop, then we're done. So that's what a waiver looks like. The other thing about a waiver is a waiver has a date on it. And the date specifically says in Ontario, specified date of MAID provision. So we are theoretically setting a ballpark kind of date when we envision where we may be going ahead with MAID. And I think in this case it's important to think about the history of where the waiver came from in Canada. So it's actually this amendment to the law is known as Audrey's Amendment. And this is from a Canadian named Audrey Parker who had metastatic breast cancer. and she had metastases to her brain. And it was approaching Christmas, and she very much wanted to spend Christmas with her family, but she was very concerned that she would lose capacity before then if she were to, example, to bleed into her brain or something of this nature. So she was forced to go ahead with MAID sooner than she wanted, and she did not get to have that extra time that she otherwise would have had if she had the safeguard of knowing that a waiver was present. So she advocated very hard for this. There's a great video on YouTube of Audrey Parker speaking to Canadians about it. It's actually a really beautiful video. And she talks about, this is why this is important, fellow Canadians, and this is why I'm doing this. So this subsequently got passed as Audrey's amendment and why we now have the ability to have a waiver. But you can get the sense that the waiver is intended for, okay, I'm kind of looking at, it's probably gonna be about six months from now, but not quite yet. I just want to know that if things go downhill because, I mean, again, the most common reasons patients lose capacity are usually twofold. Number one, it's usually if they have something that's affecting their brain, like a brain tumor, they have metastases or spread of their cancer into their brain, that places patients at risk. The second one is the medications that they are requiring for comfort and

palliation is that as people need escalating and higher and higher doses of pain medications or sedatives, it can start to impair their cognition. And usually that happens gradually. Like oftentimes people will notice it or their loved ones will notice it. And so I talk to families about this. And so the families will say like, hey mom, you're starting to get a little bit confused sometime. Maybe we should talk about that waiver. And then we can go and pay the patient a visit. And as long as they have capacity on that day to understand a waiver, to discuss a waiver, we can sign one. What we can't do is sign a waiver for five years down the road, because that's kind of almost like an advance directive and that's not currently legal in Canada. So I can't sign a waiver with a patient for 2030 on the off chance that they lose capacity before then. It's not allowed. That said, the last piece on the waiver is if it's approaching time and the date is coming for your waiver, you're under no obligation to go ahead. I'm not going to show up with my black bag and my medications. Essentially, if it's coming to that date and you still have capacity, then we can have another discussion and talk about do we need another waiver, how much further ahead, and we could look at pushing it further ahead. But generally the waivers, we're looking on the order of about six months is at the most. There's not actually a legal number in the law, but the coroner's office frowns upon anything much more than six months. So the piece about the waiver that I just want to come back to before I finish up is about the track. So as we were discussing, MAID comes in track one, reasonably foreseeable natural death. These are patients who can sign a waiver. Patients under track 2 do not have the ability to sign a waiver. They are capable. It's not that they're incapable cognitively. It is not legal under track 2. So if you are a track 2 patient and you do not have a reasonably foreseeable natural death, you've been approved for MAID, you must have capacity on the day of the procedure to give consent, which means when I come, I'm going to ask, would you still like to go ahead today? You need to just nod your head, yes, thumbs up, something of that nature. So that's what MAID eligibility looks like. And I'll just maybe cover the procedure. I think you talked a little bit about asking a little bit about what the procedure looks like. So MAID procedures can be done anywhere. They can be done at home. Most of the provisions I do are at home, but we do have a lot of hospital providers and I can do them also. We can all do them in the hospital. Sometimes people have them done at a funeral home. There really is nowhere that you can't have MAID done as long as if it's on public property. There are some special requirements, but otherwise MAID can be done. We will come to you. We will bring the medications and you would have two IVs inserted and receive 4 medications over the course of a couple of minutes that would cause you to die peacefully. Nothing happens. You just go to sleep like a general anesthetic. You don't empty your bowels or your bladder. There's nothing really to see. And then from the time the medicines have all been given, It can be variable how long it takes for the patient to actually pass away. It can be 3 or 4 minutes. Sometimes it can be 10 minutes, sometimes a little bit longer. We stay

with the patient and the family until that's done and then issue a death certificate. And then after the procedure, there's a phone call from the coroner's office sometime in the next 72 hours to speak with a loved one or family member just to verify that these were the patient's wishes, that they weren't being pressured by anyone or coerced and that they were suffering. So that's essentially what it looks like in terms of the procedure. That's what it looks like locally. And that's what it looks like from the assessment perspective. I don't know if you had anything you wanted to add about that.

QUESTIONS

Speaker 1

Are clergy allowed to be present for MAID?

Rev. Gary van der Meer

I've just been asked if I would be allowed to be present for a MAID procedure. And the answer is yes. In fact, we had a MAID procedure in December where the patient, a parishioner here, invited me to be present. And she did that because she'd already figured out that I was there to support her and that I was not about judgment at all. She had about a dozen people in the room. She took a time to speak to each person and say to them what they meant to her. And it was a very loving, safe experience that I really felt privileged to be part of it.

Speaker 2

I have a question apout numbers: Men and women, which ones are more likely to choose?

Dr. James Downer

The answer is yes. So I'll explain what I mean by that. So the numbers are, and there's been I think a bit of discussion in the media sometimes about this, so I'll try to explain it in as succinct a way as I can. So overall it's more men than women by about 52 to 48. That is because most MAID procedures are for track 1 MAID. So people who have a natural death that is approaching. It does not cause me distress to tell you that men are at greater risk of dying than women at every age. we have, our mortality rate is just higher. And often it's because of bad decisions that we make as young people. But even beyond the bad decisions, it also gets into, illnesses, heart disease, cancer rates. They're all just slightly higher in men than women. And that gap has actually been growing for the past 20 years. So just by random chance, you would expect to see slightly more men than women going for track one mate because slightly more men than women in any given year are going to develop a terminal condition. Track 2 made is slightly more women than men. The latest

numbers are about 57% to 43%. That is also exactly what you would expect to see because while women are, for a variety of conditions, women are more likely to develop but less likely to die of chronic conditions that cause frailty, for example. So this is known in medicine as the frailty paradox. Men are far less likely to develop frailty as a result of multiple conditions or a chronic illness. Men are less likely to develop it, but when they get it, they die much more quickly than women do. So men do this and women do this. is track one. This is track 2. So just by random chance, you would expect to see if you're looking at a population of people with chronic illness who are not imminently dying, not terminally ill, will be more women than men. And that's seen. When you break it down, track two, the other reason that this is important to acknowledge, the conditions, as I mentioned for track one, the most common condition is cancer. Probably the second single most common condition would be ALS. And then there's a collection of other conditions like... heart disease and lung disease and other things. For the track 2 MAID, the most common conditions are neurologic conditions. And in that category, the most common would be Parkinson's disease, which is quite common. And the other big conditions are frailty. So frailty is a syndrome. It could be a collection of conditions or one condition that drives a situation of overall frailty. And then chronic pain is the other big condition. Now it's interesting, Parkinson disease, for example, and neurological conditions, Parkinson disease is twice as common in men as it is in women. And so when you look at the track 2 numbers, men are more likely to get track 2 made for neurological conditions. Conversely, as I mentioned, frailty is more common among women. Chronic pain is twice as common among women as it is among men. 70% more common to twice as common. And again, if you look at frailty and chronic pain, you see more women than men getting tracked and made. So the numbers, I think, and I'm going to try to be charitable. There are people who approach this issue obviously from for whatever reason, personal opposition to MAID. And when they're looking at the data for data points that might suggest or you might be able to present them as concerning, that is a number that people have tried to point to in the track to MAID data and say there are more women than men getting track to MAID. Is there some issue of abuse or other problems? In fact, when about the conditions that you're talking about here and the conditions that make people eligible for MAID, this is exactly what you would expect to see. So you would definitely expect to see more MAID, more track 2 MAID among women than men and more track 1 MAID among men than women. Now, track 2 MAID is only about 4% of MAID in all of Canada. It's only about 2.5% in Ontario. So it's a very, very small number. Is that helpful?

Speaker 3

I have a question about your charge one and track two. If you've been accepted and everything is in the process of track two, something happens, can you jump to track one?

Dr. Justine Amaro

Yes, you can. If you've been found eligible for MAID under track 2 and then your condition changes such that you develop an illness that would make your death reasonably foreseeable, then you can become eligible under track 1 with track 1 criteria. The only relevant difference by then is the waiver ability. Otherwise, there's really no difference. But yes, you definitely can.

Speaker 4

I have a friend who is Roman Catholic, and she told me that in her faith, assisted death is a sin. And she wants to know if she could be buried in a consecrated cemetery.

Rev. Gary van der Meer

I can't speak for all churches, but as I mentioned, we have a friendship among our neighborhood churches: Baptist, Presbyterian, Roman Catholic, and Anglican churches. We had a conversation about this leading up to this event. And the Catholic Church does have an official teaching about the sanctity of life, which they interpret to mean that MAID is not possible. However, The Catholic priest has said he would not hesitate to pray with people for any reason, he would do a funeral in the church and a person could be buried in the way anyone else would be. Our church also holds to the sanctity of life but it does not have an official teaching on MAID. Our newsletter included some references where you could read a little bit more about our church's position. Among my colleagues There is a range of comfort level among my clergy colleagues. Clergy are encouraged to bring their conscience into pastoral matters; they may choose to be pastorally available or if they're not comfortable they would invite another clergy person to provide pastoral care. I (and most clergy that I know) would all say that I respect the medical profession and I will accompany any person pastorally. I respect the person to have made a sound decision, as which has been my experience in two instances of MAID that are known amongst some of our church community here. My intention as a pastor is to be supportive and to trust that the person has made a considered and mature decision and whatever spiritual support is needed.

Dr. Justine Amaro

I'm not going to speak to the spiritual part. I'll leave that to the Reverend, but I did want to speak about what that looks like in Ottawa. So we do have some places in Ottawa available for palliative care that do not permit MAID to happen on site. However, they do allow us as a MAID team to go in to see those patients to do assessments. And if the patient chooses to go ahead and have a provision, they will support us arranging for a transfer of that patient from that place to the Ottawa Hospital where we have a private MAID suite, which is where we can provide outpatient MAID for patients, whether they're coming from a faith-based institution where it's not permitted on site, or some patients just don't want to have MAID at home. They don't want to leave that memory for their loved ones and so we do have a MAID suite available for that. So we do have that agreement. The second piece is I will say that I've provided MAID to a number of Catholics and we've discussed this during our assessment as we often will discuss a range of topics and spirituality and meaning and these sorts of things often come up. And I've had a couple of Catholic priests attend MAID provisions quietly, and it's been fine. And so the patients who have shared that with me, their exact wording has been almost the same, which is this is between me and God, it is not between me and the church, and they've chosen to go ahead. So that's just from an experience, a lived experience perspective.

Dr. James Downar

I also wanted to say my early experience in Toronto, I worked in a large palliative care group based out of the Jewish hospital there. And it was very interesting to see that the role of faith played there because many of the individuals who were physicians practicing palliative care and practicing MAID were children, grandchildren of Holocaust survivors. And I think my interesting faith moment came when an actual Holocaust survivor was requesting MAID was being provided by the son of a Holocaust survivor with a rabbi present as well. And again, I also think that the issue of consecrated ground I think is obviously very important for many people. I think that it's important to know that MAID is not listed as the cause of death on the death certificate. It is the underlying condition that made you eligible for MAID that's listed on that. I say that not in the interest of encouraging sleight of hand or dishonest behavior on the part of people, but I think it's important to know for many people, they might be worried that if they have family members or friends that are not supportive of MAID and would not understand this, that It's not something that would necessarily be written in a very obvious and public way for others to follow. It can be, I think, kept generally a very private decision.

Dr. Justine Amaro

In Ontario MAID is not the cause of death. There are some provinces where they do write MAID as the cause of death, but in Ontario we don't. So I would agree and it's a very private decision. It's not shared in any way that doctor-patient confidentiality, nothing would be broken. The last piece I just wanted to mention about the forced transfers as they've come to be known and discussed in the news is this is currently being brought forward as a court case, the choice being made to do it in British Columbia. So right now that is where the case is being fought to try to stop forced transfers because patients should not have to be transferred when they are in their terminal stages to have a MAID procedure and so stay tuned for that but it is it's coming so we won't always have to transfer patients for MAID hopefully.

Speaker 5

Yes, I remember that you mentioned that chemotherapy could still be part of palliative care. I had a friend who was very close to death but who had chosen to try another chemotherapy group so that she wasn't eligible to go to the hospice.

Dr. James Downar

Canada's numbers have attracted a lot of attention for people. concerned about the numbers getting as high as they have as quickly as they have. So when you compare to the pioneers have made, if you will, so those would be jurisdictions like Oregon and Washington, those started out very, very rare, and those numbers have almost reached, I think Oregon and Washington have almost reached 1% of deaths, but it's been legal there for more than two decades. The other early adopters would have been Belgium, the Netherlands, and Luxembourg. And there it's been legal now again for a couple of decades. Although it was widely practiced illegally before it was legal, it was part of the culture that physicians would simply do it and nobody would prosecute it. It was so deeply in their culture. So Canada, what's interesting is that a lot of those jurisdictions hit a sort of plateau after about 10 years, and it didn't really change. But everywhere in the world since COVID, the numbers have shot up and shot up quite dramatically. So one of the things that you're seeing in Canada is we had our initial increase when it became legal for a couple of years, and that went straight into the COVID increase. that everyone has seen. So jurisdictions like the Netherlands, which had been stable at around 2 or 3%, they've shot up, so they've stayed ahead of us. So their numbers are higher than ours. And interestingly, when you look at more recent legalized jurisdictions, so I'm thinking about Australian states, for example, with laws that are similar but not identical to Canada's, you actually see a rate of growth that has been much faster than Canada's. So for example, after four

years of legalization, Canada's rate was 2.4%. Western Australia's after four years was 2.7%. But Queensland, another state in Australia, after not even three years, they've already hit 3%. So I think what you're seeing is COVID and the pandemic in general. I think we've seen also a dramatic spike in the use of palliative care and a lot I think a general drop in the use of more aggressive care like CPR and ICU at the end of life. That's been seen in many parts of the world. I think what happened during the pandemic is that it brought to the fore issues of quality and quality end of life for a lot of people. The idea that people were dying in hospitals, separated from loved ones and potentially not getting high quality symptomatic care. I think that scared people. I think people were also confronted by mortality during the COVID pandemic as well in a way that perhaps they hadn't been so directly confronted before. And I think that has raised the profile and in many people's minds raised the importance of prioritizing quality of life over quantity of life. And I think we're seeing that in a lot of different metrics. So I think the MAID numbers we're seeing in Canada are these increases have been seen around the world. The reason why Canada's numbers are higher, I think there's a couple of reasons for that. One of them is where people have to self-ingest their medication, and that's mostly the US states, and in some parts of Australia, that's the default. You have to ingest your own medication. The numbers are much, much lower. And in places where you have to apply essentially for a permit and go through a longer waiting period beforehand. So this would be Spain, Victoria, State and Australia. I can give you a whole tour. But there are a couple of jurisdictions where you have to get the permit in advance and there's a longer process. The numbers are much, much lower. So in Canada, we see these numbers where there is no you don't have to apply to get a permit reviewed and that sort of thing beforehand. And there's a much greater preference for physician administered, although both are legal. Everyone tends to get physician administered MAID. And in places where physician administered MAID is an option, it is much, much more commonly used. So that's the thing. But I will grab onto one more little factoid that I will throw at you as well. Whereas people are, I think it's important to recognize that the purpose of legalizing MAID is not MAID. It's choice. So people fixate on numbers like 4%, 5%, 1%, 2%. The only number anyone should be concerned about is 100%. Are 100% of people getting the care that they want? Because if that's what's happening, I don't know that it necessarily matters whether it's 1%, 5%, 10%, or 15%. If any number of these people are getting made and didn't want it, that would be extremely concerning to me, even if the actual number of people getting made might be very low. We should be very concerned about that. Conversely, if there are a lot of people who want to get made but can't get it because there are procedural delays or the process to get it is much harder, And that's definitely the case in many jurisdictions where it's obvious that there are a lot of people who are trying to access MAiD and simply can't. I don't know that a lower number, I don't find that reassuring to me to know that there are lots of people who

are eligible and who would want to get it and simply aren't getting it because of logistical challenges or procedural delays. That to me isn't a sign of a better system. So I think Canada does lead the world and it's not a leader in MAID, it's close, it's near the top. But we're also, interestingly, a leader in not providing MAID. I'll explain what I mean by that. Justine mentioned this before. If you start the process of MAID, even people who are found eligible for MAID, the most likely outcome of that process is not MAID. There are a tremendous number of people who are not found eligible. There are a tremendous number of people who are found eligible, but die naturally before they receive MAID. And there are a very large number of people who are found eligible who are just like, thank you. I feel good now. I feel good knowing that this is an option for me. That actually, that alone, just finding the finding of eligibility was enough to reduce their distress that they didn't actually feel like they needed it. And you never hear from these people again. They disappear. And that's really an important point to say is that That to me suggests that, I think that the way that our system is working is, I think it is providing people with choice, which is I think what it's about. But again, I recognize that a lot of the focus is on numbers.

Dr. Justine Amaro

The only thing I wanted to add was the palliative care piece. I know we talked earlier about how discussion about palliative care is going to be a mandatory part of a MAID assessment. But one of the fallacies that you will hear in the news commonly is this idea that, well, patients are getting MAID because they couldn't get palliative care. And I can just tell you that we have robust data that refutes that. On every MAID death report that I complete, the boxes, did the patient receive palliative care, was palliative care available to the patient? And the answer is universally in this region, yes, it is. This is not to say that there are no people anywhere who perhaps can't access palliative care. There are some rural areas, there are some other situations where perhaps a patient can't for whatever the reasons are, whatever the social determinant of health might be. But that is a common fallacy that it's important to just be aware that people are not choosing MAID because they could not receive palliative care. The patients I see, in fact, it's the definition of one of the criteria of MAID is that you are experiencing intolerable suffering that cannot be relieved in a manner that is considered acceptable to you. That is what the law says. So that doesn't mean that if X, Y, or Z palliative care is available, if I could give you more medications to take away your pain, you don't have to take it because you find it still intolerable that you can no longer get up out of your bed. You can no longer get yourself dressed or make a piece of toast. Everyone's experience of intolerable suffering is different, but people are not choosing MAID because they don't have access to palliative care.

Speaker 6

My father, who died almost 10 years ago, just shy of 90, spearheaded a campaign to establish a hospital for palliative care, but it was a very supportive debate as well. And he always said, in my day, we're back to the point we created by our era. People lived too briefly and died too quickly, but now people live too long and died too slowly. So here's a numbers question, but it's not a data question, it's a speculative point. As people live longer, not necessarily better because we have illnesses that are managed, we anticipate MAID increasing due to people living longer but more difficult.

Dr. Justine Amaro

I would say yes, because that's certainly the experience of a lot of the patients I see who I'm assessing who are in their late 90s or early hundreds. I mean, sometimes I get a consult where essentially the consult says, tired of life. Which sounds a little bit funny and one goes in thinking, are you going to be eligible for MAID because you're tired of life? And it takes some deep exploring and there's a lot of meaning in that journey. Sometimes that is all of my friends have died. My partner has died. Maybe their children have died. I'm socially isolated because I am so frail that I can no longer go out and engage in the activities that would have given me pleasure. Sometimes it is identified as tired of life, but really when you explore it more, it's like, well, actually, I can't see anymore, so I can't read a book. I can't hear anymore, so I can't have meaningful conversations. I can't ambulate, so I can't get out of my bed, and I have a lot of pain, and I have X, Y, and Z. So these things are what we would call the syndrome of frailty, right? Or as we put on the death certificate, multiple comorbidities in a person of advanced age. In other words, there are enough things there that when you're 102, chances are your death is probably reasonably foreseeable. So frailty is a big spectrum, and while some patients can have multiple comorbidities and fall within track 2, some particularly that these advanced age patients can fall within track one also. So I would say yes.

Dr. James Downar

I'm sort of a definite maybe. You're asking a wonderful question and I will try to keep my speculation brief. But as I was trying to allude to, what we have seen even before COVID is there's been this sort of generational international pan-cultural shift in what end of life care looks like. This has gone on since before I was born. But the minute somebody invented CPR, all of a sudden it became the thing that everyone had to have. And that was back in the 1950s and 60s. And all of a sudden, then we suddenly had to create rules where we were allowed to not do it because it actually took several iterations of CPR guidelines before anyone even acknowledged that it might not always be a good idea to do CPR on

somebody. There was a big international study in Europe done looking at end-of-life practices in the ICU between 1999 and 2018, so about over 20 years of change. And what they found, even though there were no changes in laws across any of these places, so we're looking at a change in law in Canada, and after 10 years, our MAID numbers hit 5%. That's A 5% change. If you look at the changes in end-of-life care in the ICU, people not getting CPR, people not having tubes withdrawn and being allowed to be comfortable at the time of death, that changed almost 20%. in 20 years. So we're seeing similar changes. It actually only became legal to withdraw life support in Canada in the early 90s. And within a decade, more than half of deaths in ICU were preceded by people withdrawing life support. So I think we are seeing across the board people fundamentally, I don't know if that's necessarily the same thing as talking purely about quality of life, but maybe a more overt appreciation for the limitations of what we can achieve through medicine in terms of quality of life and prolonging life that people would enjoy. I want to pick up on what you said about activities and about identity because the number one, the thing I didn't say was the number one reason why people get made is what we call it existential distress. Now people have written PhDs on what existential distress actually is and there are many people who believe it's kind of like, it's like spiritual distress for atheists. I would put it that way. But I think maybe in a more helpful way, I could describe it as a loss of purpose. And again, we go through existential crises and distress periods in our life around difficult life events, transition to adulthood, the loss of a job, the loss of a life partner, and then when you get a terminal illness. But it's important to understand that humans are relational beings. We define ourselves in terms of our network and who we are to others and what we do with ourselves. That's vitally important to our identity. So if you look, hi, tell me about yourself. Well, I'm a father. I'm a doctor. I do this. I'm a trainer on a hockey team. I like digging holes in the sand and making sandcastles. People will talk about those things. When an illness takes away your ability to do the things that that gave you purpose, gave you meaning, that is not just a decline in function. That's an assault on your identity. That's how people view that. And that's important to understand. When so much of our relationships with others is also based on common interests and common activities. So if I have a condition that takes away my ability to do the activity through which I form my network, My network's gone. It's hard. So this is why when we talk about loneliness and the loss of our social network, as a result, it's deeply tied to the illness. And as much as it may be nice to have a teenager come and play piano or play cards with you once a week, it's not quite the same thing, right? Like simply parachuting another person in to keep you company is not the same thing as your community that you had around your illness. And that's, I'm not saying, by the way, let's be clear, I'm not advertising made for people who lose their function and their ability to do their activities. I don't want anyone to get made, please. But I just want us to have a solid appreciation for when someone comes to you and

saying, I can't read a book anymore because I'm blind. It's a societal thing. We're imposing these limitations on people, et cetera. I don't know. I don't see it that way. I think that when a condition, a medical condition, takes away your activities that gave you joy and gave you pleasure, takes away the common interests that enable you to form the network that you formed your whole life, I see a lot of people in that situation and it's not a very fixable problem. It's very hard to fix. So I just want to put that out there. So to your point, sir, you ask about will this living longer but not better thing lead to more MAID. I could see it doing that. But let's also, the other thing is, of course, when you look at who gets MAID, it's not the people that actually have chronic conditions that change slowly. It's actually the people who have more acute conditions that change quickly. Cancer and ALS share only one thing in common and that's the rate of decline. But people with heart disease or frailty, these are much more long-term things with slower changes and their rates of MAID with those conditions are exceedingly low. Even though their needs, their dependency is higher, their level of function may be lower overall, their desire for MAID is much lower. So I think it has something to do with loss of ability, but it has also a lot to do with how quickly that happens.

Speaker 7

You can have mental illness, but it can't be your only cause. Is that the case?

Dr. Justine Amaro

Yes, currently it's a federal law that is being looked at and folks are probably aware it came up in the news a few years ago. There was a sunset clause. It was due to expire. It was going to be happening and it's being robustly debated among a bunch of amazing psychiatrists, some of whom are vehemently opposed, some of whom are great supporters. Both sides have great arguments. I have my own opinions about it. But at the end of the day, currently for now, it is not legal if it is your sole underlying medical condition. I suspect it'll be coming. I doubt it'll happen when it is due to expire this time. I don't know. It's just a prediction. And I think the second piece is going to be when it does become legal is how accessible will it be? Because we already know that the mental health, availability of mental health professionals and particularly psychiatrists we need them already for very severely mentally ill patients. And even there, there's already a shortage. So I can tell you that in our region, it's going to be very difficult because there are just not enough psychiatrists around. And it is almost certainly going to be, again, no guarantees, but almost certainly it's going to be a requirement that if you are able to be found eligible for MAID as a sole underlying condition, if that becomes legal, almost certainly one of your assessments is going to need to be done by a psychiatrist. And there

will be a number of other things that'll have to be met, which will be in the mental health domain. So currently, no.

Speaker 8

We have two questions: Number one, if I had a diagnosis of early dementia, am I eligible to be diagnosed with galloping dementia? Second: Can you explain to us the difference among palliative care, end of life care, and comfort care?

Dr. Justine Amaro

How about I take the first question and Dr Downar will take the second question. You're a palliative care physician and I assess lots of patients who apply for MAID because of dementia and I find many of them eligible, not all of them. Dementia is tricky and I'm very transparent with this about patients who do apply for MAID with a diagnosis of dementia. The first thing about dementia is not all dementia is created equal and different dementing illnesses have a different trajectory. So something like Alzheimer's disease is narrow degenerative. It has a fairly predictable course. We know what's going to happen over a course of time and we know what it is going to look like probably over the course of maybe 10 years unless there are complications in the meantime. from the time initially noted to the time of death, if you were to die naturally. Again, don't quote me on exactly 10 years. Of course it's different, but Alzheimer's is one type. There are many other types of dementias like Lewy body dementia or frontotemporal dementia, but another one that I see often is vascular dementia. So these are patients who have strokes. Not big, huge, catastrophic strokes necessarily that cause them to pass away, but little strokes. You look at their CT scan and they have little, we call them lacoons, little strokes all over the place. And it causes them to gradually experience cognitive decline. These patients have a very different trajectory, not necessarily predictable in the same way. So that's the first piece about dementia, is looking at what is the type of dementia, what do we know about the trajectory, what is likely to happen. The second piece about dementia is that yes, you can be found eligible for MAID under track 1 for dementia. However, at the time of being approved, you must meet the criteria for MAID eligibility in Canada, which again, just to go over, and I actually do discuss these again when I do a dementia assessment, you must have, number one, the grievous and irremediable medical condition, check. You've been diagnosed with Alzheimer's, you've met that requirement. Number 2, you must be in an advanced state of irreversible declining capability. So if you have just received an Alzheimer's diagnosis, but you're still driving your car, going about your business, getting your own groceries, doing your own finances, you're functioning at a very high level, you do not meet that criteria yet. That would be an advance directive. That's starting to happen in Quebec. It's not happening in the rest of Canada. I think we will see it at some point, but not yet. And then

the third piece is intolerable suffering. And this is one of the most interesting pieces about dementia, actually, which is oftentimes when patients are first diagnosed with dementia, they do undergo a lot of suffering. As Dr. Downer mentioned, we call it existential suffering. Even something we call anticipatory suffering, like what is going to become of me? my family are going to need to care for me, or I'm not going to be the person I am now. I don't want to live through what that's going to look like. That's very real suffering. So the suffering criteria for most patients who take the time and energy to apply for MAID for a dementia diagnosis is usually met in the beginning. The tricky part though is the decline. You do need to have an advanced state of irreversible decline in capability. And so this is where it gets a little bit more tricky because what we know about many dementias is that as they progress, our insight into our suffering changes. And what we may have found intolerable or what we may have found intolerable as an idea as a non-demented person, a person who still is fully cognitively intact, they get a diagnosis and are very distressed about it, when they are six or seven or eight years into their dementia, they may no longer have awareness of that suffering. And they are happily in a long-term care facility, visiting with loved ones, playing bingo, going to the mall, finding meaning in other places, and they're actually not suffering intolerably anymore. And if there is not intolerable suffering, you are not eligible for MAID. And that means you must have intolerable suffering all along. So it's tricky. So then this raises the even more complex question of, well, what about the waiver? Because maybe I could sign a waiver when I get diagnosed with dementia and that way I can be covered so that if at a later time I'm suffering intolerably, my family can call you up and say, hey, we have this signed waiver. Well, we know the first thing about the waiver. It can't be signed several years down the road. So that's the first tricky part. The second tricky part, again, is as insight changes in dementing illnesses, patients may no longer want MAID. It's very conceivable they may have wanted MAID initially, but when I come to see them, I may show up and say, hi, I'm here for your MAID procedure, and they say, why? I'm going to bingo. Why are you here? Or I don't want you to do MAID. I'm busy or I'm happy or whatever. So there's that piece. And you can imagine then there's a few elements to that. One is the legal piece. The second part that we MAID doctors like to talk about is also on a philosophical level, are you actually the same person before you were demented as you become when you develop dementia? are your wishes actually just as valid as a demented human, person with dementia, and maybe your wishes have changed and you have lived into something that you didn't foresee, but life's actually okay. You don't mind that you can't do the things that prior undemented you would have been upset about. So it's really tricky in that part too to determine what is a person's wishes? And this is where I think it's really fraught with what's happening in Quebec. And I say that as someone that's welcoming of the idea of advanced directives, because it's going to be very tricky. Because I can tell you, as a MAID practitioner, showing up to do a MAID provision to a happily

demented person who's playing bingo and says, like, I don't want MAID, what are you going to do? Right? Like, you're not going, number one, from a moral distress perspective, I wouldn't be able to sleep at night to put that person to sleep. And it even raises logistical and legal questions because the logistics for some patients, I will have this discussion and they'll say, well, Dr. Merrill, can you just sedate me in advance? Like, can you give me some medications so that you'll let me, I'll let you do it. I'm like, no, not really. I can't. But this is a discussion when you start thinking about advance directives that this may become part of the practice, right? There may be an agreement that like, okay, this is part of our practice, you've set out this advance directive, you want me to carry out MAID, I may come, you may be in a happy state of dementia playing bingo, and you want me to slip something into your coffee that is going to make you be sedated so I can carry out the procedure. We may see that. I don't know. I mean, it's so early now with what's happening in Quebec. But there are a lot of logistical challenges to MAID and dementia. But the simple answer is, MAID for Alzheimer's dementia is considered a track one indication, and if you meet the criteria of advanced state of irreversible decline in capability and intolerable suffering, then yes, the capacity piece is the last piece, is that on the day of the assessment, you absolutely have to have the capacity to understand the whole discussion and go through all of this. And on the day of the procedure, you either need to have the capacity to understand what's happening, which means that for patients who I've provided MAiD to with dementia, they're usually going ahead a little earlier than they ideally might want to, but they're doing it because they realize that if they wait any longer, it's a risk that they'll lose the chance. Or sometimes we can wade into the possibility of a waiver with careful check-ins along the way with dementia patients where I say, well, you're not eligible yet. let's check in and see how you are in six months. In six months down the road, I pay them another visit. Maybe they've lost their driver's license. Maybe they can't make meals anymore. And we start to get to that point where they do meet what I would determine to be an advanced state of irreversible decline. And then it's very careful check-ins to decide if there is a role for a waiver. Although waivers in dementia are really tricky because again, on the day of, if the patient says no, then we're done. I hope that answers your question about MAID in dementia.

Dr. James Downar

Regarding the second question about palliative care, end of life care, hospice, these are terms that are sometimes used interchangeably and they're all probably a little bit different. I'll try to make it as clear as I can. Palliative care is a type of care. It's not a place and you know, we often say, oh, they are, this person is palliative. You'll hear, oh, he's palliative now. You don't become palliative. It's not really an adjective we should use to describe people. Maybe me, you can describe me that way if you'd like. But when we use

that as a shorthand in medicine to say, oh, he's palliative, which generally means that someone is at or near the end of their life and we're focusing on comfort. But strictly speaking, that's not a correct way to use the term. So palliative care can be provided, as I think others have pointed out, at any phase of an illness, of a serious illness. It is very commonly provided alongside attempts at curative care. So if you're, for example, getting treated for cancer and you're having a lot of symptoms, a palliative care team member can get involved to try to support you and keep your symptoms well controlled while the oncologist is giving you the unpronounceable drug to treat your cancer. But we are increasingly moving away from outside of cancer as well to try to make sure that we're doing the same type of integration of palliative care for people with all sorts of non-cancer conditions. So we have a really good integrated system now for non-cancer palliative care involving liver disease, lung disease, and kidney disease here in Ottawa. I'm really proud of that, by the way. Some of my division members set that up and we built a really good service. We have a neuro palliative service, a palliative service that's just for people with neurological conditions. And they are working full time and they're like a world leading team right here in Ottawa. Very proud of them. We have a heart failure team based out of the Heart Institute. Dr. Caroline McGinty, as a cardiologist with palliative care training, runs that team. Excellent team. So you can get palliative care specialists who are hopefully involved in your care pretty much regardless of what condition you might have. Now, that's not to say that all palliative care has to be delivered by somebody who carries the palliative care card in their pocket and has done a fellowship like I have. what we call primary providers, people who aren't specialists in palliative care, can be really good at providing palliative care. So they can be really good at symptom management, et cetera, as well. So we want to promote the idea that palliative care is everybody's business, and every physician and nurse practitioner and every healthcare provider should be able to provide some degree of palliative care. And for the more complex cases, they'll involve someone like us, like the specialists. And that's where we're trying to go. So that's a type of care. There are palliative care units that are typically for people at or near the end of their life. And there are hospice units. Those are like Hospice Care Ottawa. Has three of them in Ottawa. So you have Ruddy Shenkman out in Kanata. You have, I'm blanking. Thank you, May Court, good grief. May Court here in central Ottawa. And for the past couple of years, we've had the Maison de Leste, which is right across from So we have it east, west and center we got you covered. And of course there's the big palliative care unit at St. Vincent Hospital as well. So those are physical units. units that do palliative care as well. But we have consult services at all the hospitals that can also help provide the palliative care as well. And most end-of-life care does not happen in a palliative care unit, so you can hopefully get good palliative care. You don't have to go to a palliative care unit to get that. And we're trying more and more to make sure with our consultants and our other teams to

get out there to make sure that nobody feels like they have to come to a hospice or a palliative care bed to get that. I hope that's helpful.

Speaker 9

If I’m declared to be eligible for MAID, is there a finite amount of time or do I have to re-apply?

Dr. Justine Amaro

If you're found eligible for MAID, it never expires unless you no longer have a grievous and irremediable medical condition and you're cured.

Speaker 10

In the book Faith Seeking Understanding, it is noted that method one includes intravenous and you are gently put to sleep. Could you explain what they call method two, which is a sub-administered MAID?

Dr. Justine Amaro

MAID comes in two options in Canada. There is IV and there is oral. At the provision, there's usually just one physician there actually providing, although two people have approved it. The oral method, although it is legal, I can tell you based on a recent case where we tried very, very hard to provide oral MAID to a patient that wished for this. It is not available in the Ottawa region. We cannot get the drugs from the pharmacy. There is no pharmacy that will dispense them. It is not actually possible where we are, no matter how hard we as a MAiD team try and the physician who worked for this worked around the clock to try everything possible to get these drugs. So locally, the answer is no oral MAiD. But yes, it is legal and there are places in Canada where you can get it. is a very small number of patients who choose it, but it is legal, just not locally available and probably going to be a barrier in multiple other places, unfortunately.

Speaker 11

I understand palliative care is given as you're approaching the end of your life. What is it? What do they do?

Dr. James Downar

I realize we're close on time, so I'll try to briefly summarize my entire career. So the main components of what we do, number one is meticulous attention to symptom management. Those may be physical symptoms like pain, shortness of breath, nausea. They may be other symptoms like pruritus, itchiness, sometimes difficulty sleeping, and

sometimes people are very agitated, delirious as they approach the end of life, we'll try to calm them down. So symptom management. We do care planning, so care planning with the individual to clarify their goals and try to make sure that our care plan matches what they're hoping to achieve and bring that together. That may involve meetings. We try to support family members as much as possible. So that would be supporting family members during the course of illness, giving caregiver support. But then also in the bereavement period, trying to provide bereavement support as well. Fair bit of research in that area. Those are the main sort of dimensions of what a palliative care team might try to address as they get involved and what others trying to do palliative care might do. So that will look a little bit different for everybody. A lot of it depends on what your specific needs are and where you are in the trajectory and what your goals are that we try to sort of put that together. Also in combination, if you have an oncologist or a cardiologist or somebody else who's helping to manage your illness, if you have a primary condition, we try to coordinate with them and make sure that our treatments and their treatments are going to work together and not be at cross purposes. I'm sorry, that's a very short answer to a very good question.

RESOURCES

Dr. Justine Amaro

If you're leaving tonight wondering more things than you feel like you've come to understand, there are a number of great resources that we refer our MAIT patients to that are online. One is called Bridge C14. It's a website and it has real people there with real lived experience. It is free. Dying with Dignity Canada is an organization that is available to provide support throughout the journey as well as information really at any stage. And then MAID Family Support is another one, another website, which is excellent for helping to guide family members or loved ones as they're going through this. Finally, when you see these catchy things in the media that sound quite distressing regarding MAID, there's an excellent group called MAIDmisinformation.ca. You can go to the maidmisinformation.ca website and they pick up on all of the news internationally as well as Canada-wide specifically and they look at it from a factual perspective and address what the actual facts are about MAiD.

CONCLUDING EXPRESSION OF THANKS

Rev. Gary van der Meer

Thank you Dr. Downar and thank you Dr. Amaro. Thank you very much for helping us with this. And to all of you, thank you for coming. I know you've come with many questions. Maybe they're very personal and they're about your own plans and thoughts. A church is a caring and safe place and if you would like to come and be in this space or know that clergy pray for you or that people of your community pray for you, come and talk to me. We want to make sure you have support. I'm going to ask Reverend John Perkin to come and send us off with a closing prayer and blessing.

Reverend John Perkin

We probably all know the 23rd Psalm that says even as we walk through the valley of the shadow of death we will not fear for God is with us. I think we have walked through the valley of the shadow of death in some way this evening and we know God is with us. So let us pray. God of creation, life and death and resurrection, even as we have entered into discussion about death and dying, so we affirm your gift of life. We give thanks for open and honest conversation here. We give thanks for those who care for the ill and dying in hospitals and hospices and care homes. We pray for those who struggle with decisions about life and death. for families who grieve the passing of loved ones, for doctors and nurses who ease the transition from life to death. We give thanks, O God, that you are present in life to give it dignity and meaning, even as you are present to offer dignity and meaning in death, inviting us to the gift of eternal life. May we live as those who know meaning and joy, and may we die as those who have lived with meaning and purpose, And so may we die knowing dignity and peace. Send us now into your created world as those who live for you, serving your world and caring for others. Send us into your world of beauty and life as those who know joy through all our days. Support us now all the day long of this troubled life until the shadows lengthen and the evening comes and the busy world is hushed and the fever of life is over our work is done, then in your mercy grant us a safe lodging and a holy rest and peace at the last through Jesus Christ our Lord. Amen.