

Dementia Dialogue MAID& Medical Assistance in Dying

Transcript of interview with Dr. Mariette Brennan

David - Welcome to Dementia Dialogue. In this episode, we will be joined by Dr. Mariette Brennan to discuss medical assistance in dying, specifically Bill C-7. Dr. Brennan teaches Constitutional Law and Health Policy at the Faculty of Law at Lakehead University.

Medical assistance in dying or MAID, as it is often referred to, is fraught with complexity because it challenges us as a society to consider what it means to be alive and to die.

These are deeply personal questions with centuries of cultural and religious thought and values attached to them. In our pluralistic modern world, it is not surprising that we struggle to find a shared understanding of what it means to be alive and to decide how to end it.

Our episode today is intended to help us understand the issues surrounding Bill C-7, but not to present one or indeed any particular position either on MAID or on the changes proposed in C-7 or indeed on the things that C-7 does not address at the moment.

Thank you, Dr. Brennan, for agreeing to join us today and to help our listeners become more informed about medical assistance in dying in Canada, Bill C-7, which is currently before the Parliament, and some of the fundamental issues underlying the evolution of medical assistance of dying in Canada, otherwise known as MAID, especially as it pertains to people with dementia.

So I'm wondering to begin the conversation if you might just provide some background and help us understand how we've come to this issue with Bill C-7 being presented to parliament at the moment.

Dr. Brennan - I would be happy to. The issue of MAID is not anything that's new. In fact, if you look at the entire history of MAID, it goes back decades. And so we first heard about MAID coming out in the early 90s. It's when it really sort of got its first major push. And that was when it came out in the Rodriguez case. Sue Rodriguez was suffering from ALS and she had wanted to seek medical assistance of dying.

Now, I think what's important for everybody to understand is why we need to have these cases in the first place and where medical assistance in dying is actually situated in Canadian law. And what most people don't realize is that medical assistance in dying is covered by both jurisdictions. So there's provincial laws that deal with it and that deal with it from the health care perspective. So you have laws dealing with how it's dealt with through various individuals who can provide it through physicians, where it's dealt with in provinces. But then you also have it mainly situated in federal jurisdiction and the federal government has in fact legislated it using the Criminal Code of Canada.

So that became the issue, is that providing assistance or providing any sort of assistance in somebody's death was a criminal offense under Section 241. And so that's where the medical assistance in dying cases came from, was this decision to try and overturn what is in fact a criminal law prohibition. So that meant that if somebody violated it, it wasn't just this moral punishment. There was, in fact, a criminal code conviction that went along with it that necessitated jail time in all of these different situations. And so that's what was, in fact, being challenged.

And so Rodriguez wasn't successful in having that legislation struck down. So what ended up happening is we had intervening decades where we saw other countries starting to make changes to their laws, which started to allow medical assistance in dying.

We finally got a case back up to the Supreme Court in 2015. And in that case, Carter, the Carter case, as we all know it, again, the question was whether or not the laws that created this criminal law prohibition on medical assistance in dying was in fact valid, or did it violate our Charter and our Constitution?

What ended up happening is the court struck it down and they struck down the prohibition under Section 241 and they told Parliament, "Parliament, you have the opportunity now before it becomes fully effective, to go forward and create a law that allows for medical assistance in dying."

For anybody else still assisting in suicides or in death, it's still illegal but they were carving out an exception for individuals to access and have help from medical assistance. And it can take two forms. It can either be self-administered, so prescribed by a physician and then you administer it yourself or it can be physician assisted where the physician, in fact, administers the medication.

Parliament was left with about one year to create this new law. Unfortunately, what also happened at that same point in time is we had an election. And so when they sought a little bit further of an extension on creating it and we ended up getting Bill C-14 put into place and Bill C-14 was in fact drafted in a way that was meant to meet the basic requirements of the Carter decision. So what the Supreme Court highlighted as the biggest issue. And that's pretty much all it was meant to do.

And so when Bill C-14 was drafted, Parliament in fact acknowledged that, "Look, we're not even dealing with some of the biggest issues." Right? They highlighted the fact that they didn't talk about advanced care directives. They highlighted the fact that they didn't talk about whether or not individuals under the age of 18 or "mature minors" (as they're sort of known now) can in fact avail themselves to it. They didn't acknowledge whether or not mental health illnesses could fall under it. And so they pretty much looked at what the court recommended in Carter and said, "This is what we think the legislation should do." And then they said, "We will have individuals look at this legislation later and we're going to review it. And all this this is just sort of the very first compliance."

When they created this law, they had put in certain requirements or eligibility for people to be able to avail themselves to medical assistance in dying. And one of the things that they created was that anybody who is going to seek medical assistance in dying had to have this grievous and irremediable medical condition. Part of that also required them to have a natural death that was reasonably foreseeable. That all sounds great on paper, but if you ask me what a natural death that is reasonably foreseeable means, it's probably very different than what anybody else thinks. And so when you put in these terms and you make them conditioned and you don't define them, you start having problems.

And so what ended up happening is we had more challenges related to medical assistance in dying and more legal challenges related to medical assistance in dying. And those pushed us to start looking at how to restructure the law. And that's sort of where Bill C-7 was born from.

So Carter led to Bill C-14 and Bill C-14 in order to be eligible for medical assistance in dying, there were certain criteria that you had to meet. The first is you had to be eligible to receive health care services in that particular province. And so that is to ensure that we don't end up having tourism or that sort of issue where we have individuals coming to seek medical assistance in dying that aren't eligible here in Canada.

Then you had to be 18 years old. And again, that issue was flagged as whether or not that needs to stay and what we're going to do with people under 18. There were capacity requirements and then there was that requirement of a grievous and remediable medical condition. And that meant that you had to have a serious and incurable illness, disease or disability. It didn't have to be a fatal one. So that didn't have to be the cause of your death. But you had to have a serious, incurable illness, disease or disability. You had to be in an advanced state of irreversible decline. You had to have intolerable physical or psychological suffering.

And so as that was a subjective sort of test, as an individual, you had to claim that you had this physical and psychological suffering. And then you had to have the natural foreseeable death. You also had to make sure that the request was voluntary so people weren't being coerced or pushed into it. And then you had to have informed consent requirements that happened when you requested it as well as before it was administered.

And these sort of became some of the flash points. And so what happened in Quebec is we had a case called Truchon and the Procureur General du Canada, which is the attorney general of Canada, and Truchon. Truchon was one of the plaintiffs. There were two plaintiffs involved. So there was Truchon and Gladu. Both of those individuals suffered from an incurable disability. So Truchon himself had Cerebral Palsy and Gladu had Post Polio Syndrome, which was starting to have severe impacts on her life.

Now, the problem with both Gladu and Truchon is that while they had this serious and incurable disability and they had the advanced state of irreversible suffering, their death wasn't naturally foreseeable. So it wasn't going to be a natural death that was reasonably foreseeable. So they met all of those criteria and they had properly contemplated it and had made a decision to seek medical assistance in dying, the problem was, is they didn't meet the full criteria. So they challenged the law. And you had a judge in Quebec essentially decide that the provisions related to the natural death that's reasonably foreseeable is unconstitutional. And so they said, "We're going to essentially suspend the declaration of invalidity and we're going to give parliament a chance to rewrite the law."

At this stage, Parliament could either seek an appeal and try and go to a higher court and see if the law would end up being upheld in a higher court, so at the Quebec Court of Appeal or at the Supreme Court of Canada, or they could say, "You know what? Let's just try and change the law." And so they opted to just change the law.

And so what they ended up doing was they created Bill C-7, and that's the one that's currently debated. The court deadline runs out on December 18th of this year. So it's supposed to be passed by December 18th. And what this clause and what this new bill does is it essentially has or creates two separate tracks for individuals seeking medical assistance in dying. And what that means is that they acknowledge that in some instances you're going to have individuals who are seeking medical assistance in dying whose deaths are reasonably foreseeable. If that happens, they're going to have a different process and a different safeguard. For individuals whose deaths aren't natural deaths that are reasonably foreseeable, they're going to follow a different path and there's going to be

different protections put in place to protect them. And so they're creating essentially an entirely new system to deal with what happened in Truchon.

David - Yes, in some ways, it seems as though that we've kind of got two tracks here depending on foreseeable death. And in some ways, Bill C-7 removes or simplifies the regime for people in terms of reasonably foreseeable natural death than Bill C-14 had.

Dr. Brennan - It does, and that was one of the things that they wanted, because there was a lot of criticism attached to some of the procedures in Bill C-14. And so one of the ones that was extremely problematic was this ten day wait period under Bill C-14. And so what essentially that meant is that you had to make your request for medical assistance in dying and there are requirements that the request must be in writing under Bill C-14. You have to have two witnesses. You would then have to have two doctors or nurse practitioners assess you, check your eligibility and confirm you're eligible for it.

And then you would have a wait time of about what was supposed to be ten days from your request to when it could in fact be administered. The problem is, is that during that ten days of wait period, you are in fact still suffering or individuals can still be suffering because these are people whose deaths are naturally foreseeable.

Most of the time, people don't enter a decision to seek medical assistance and dying lightly. And so they are at this point in time where this ten day wait period doesn't really do much besides prolong suffering.

What they've done in Truchon is they've removed that ten day wait period. One of the reasons for doing so is that in those ten day wait periods, you can have a decline in capacity and that's your ability to actually accept your medical decisions or consent to your own medical decisions. And so when you are getting to the point where you might have had to be sedated in order to deal with your pain and suffering, that was a result of your incurable illness, you would, in fact, have to withdraw the medication to ensure consent happened at the time of being administered. And so it caused all of these different issues coming up.

What this, in fact, did was it allowed people to say and acknowledge that, "Look, if I'm making this request and I have a reasonably foreseeable death, I know what I'm doing. I'm not taking it lightly. And once the doctors agree that I meet the eligibility, I shouldn't have to wait ten days". And so that was one of the main shifts that you saw.

Interestingly enough, the other shift that you saw was this idea behind the final consent. So before what would happen is you had to consent on the day you requested medical assistance in dying and you had to have your ten day wait period and then you had to consent just before it was administered. So you had two different times when you had to have capacity and had to consent. And so they have now actually created a new law that allows a waiver of that final consent. And so that means you can ask for medical assistance in dying, knowing that your death is reasonably foreseeable. Acknowledge that, "You know what? I'm requesting it today, but I don't want to receive it today". And you can make a plan for a little bit in the future. And in that future, you're not going to have to re-consent.

There are obviously very strict requirements around that, including the fact that it only applies if your death is reasonably foreseeable. So I can't on the day I'm diagnosed with an illness or a disease all of a sudden say, "You know what, in ten years, this is what I'm

going to make my decision.” It has to be death is reasonably foreseeable. You had to have been approved and already assessed for medical assistance in dying so you've already had to go through and had two doctors assessed and approved you of medical assistance in dying. And you've had to make arrangements with your practitioner, which means that you have actually had to schedule the procedure and know what date you've agreed to. So it's not the same thing as an advanced care directive, but there is some waiver and a little bit of wiggle room that's now built into it.

David - Now how about then in terms of the other category of people who are eligible for medical assistance in dying?

Dr. Brennan - Well, this is essentially what is responding to the Truchon case, right? So in Truchon they didn't have reasonable foreseeability of dying. And so what happens in this particular case is they're put into a different track. And so if your death isn't reasonably foreseeable, they have gone through and said, “OK, the request for medical assistance in dying still must be put into writing. It still must be signed by an independent witness.” Again, there's only one instead of two, like what we saw under Bill C-14 for both of them. So that's a little that's changed a little bit.

They have to be informed that they can withdraw the request at any point in time. So even if you make that request, it doesn't mean you have to follow through. And that is the same for either track.

Again, you have to have two doctors assessing your eligibility, but here's where there's a little bit of a differentiation; when the death isn't reasonably foreseeable, when you are choosing the two doctors to assess your eligibility or when you have your two doctors or nurse practitioners assessing eligibility, one of those doctors has to have expertise in the medical condition that you are suffering from. So they must have that. And they do say the word suffering because suffering is still part of the condition, right? That you must have that level of tolerable pain and suffering.

Then they also at that stage must discuss with you options for different services to alleviate your pain and suffering. So they have to include talking to you about counselling services, mental and disability support and services, palliative care. You must also be offered consultation with those practitioners. And so that adds another layer.

And only after the practitioners that are assessing your eligibility and the person requesting MAID are able to show that the person has seriously considered these other options, are they then eligible for medical assistance in dying.

And typically there's a ninety day waiting period. So they've extended the waiting period a little bit longer in these particular cases, those can be waived if capacity or loss of capacity is imminent. So there is a little bit of acknowledgment that it can be waived, but they still want to essentially extend it a little bit more. And again, before administering medical assistance in dying, the person must consent and be provided an opportunity to withdraw their consent.

And so you see them taking some of the stuff that was the throw back from Bill C-14 around the consent just prior to it, the wait times and that goes into individuals that are suffering but death is not reasonably foreseeable.

David - So there are safeguards. There are additional safeguards, if you will, in that second track of people, some of which existed in the original C-14, but have now been isolated to that particular track only. Yes, okay. Are there any other points in terms of the fundamentals of the law, the changes in the law that are being proposed and the processes that you think listeners need to know before we move on in our conversation?

Dr. Brennan - Well, I think one of the important things to note is that a lot of the outstanding issues from Bill C-14 haven't, in fact, been resolved. And so in 2016, they had asked the Council of Canadian Academies to look at this idea of mental health as an underlying or the sole reason to request medical assistance in dying

In Bill C-7 they in fact said that mental health or mental disability is not a sole reason for allowing medical assistance in dying. So they did carve that one. But they also asked the Council of Canadian Academies to look at mature minors. And more significantly for the audience, advanced care directives. And advanced care directives was something that was widely endorsed by the Canadian public. So before C-7 was actually tabled in Parliament, they had gone through and held widespread consultation with the Canadian public. Over three hundred thousand Canadians responded to the survey. Seventy nine percent of those individuals were in favor of advanced care directives for medical assistance in dying, and they still haven't been incorporated into the legislation. There are obviously those waivers built in when there's the reasonable foreseeability of death where you can schedule your procedure but they aren't this full some acknowledgment of these advanced care directives, which is something that had been studied in 2016 (reports were released in 2018). It's something that was a flashpoint for Canadians. So that still hasn't really been addressed in Bill C-7.

David - How do you see the government proceeding to try and address that issue of advanced directives, the seemingly overwhelming support within the populace (if we were to take that consultation as a true measure of what people think about it)? Yet there's still a reluctance amongst decision makers about it, including that in a legislation. What devices are available to the government to try and reach some consensus or to reach what might be thought to be as socially acceptable law around advanced directives?

Dr. Brennan - Well, one of the things that has typically happened has been reliance on other jurisdictions, right? So we look at the experience in other countries that have adopted these procedures. An advanced care directive isn't something that's commonly found in a lot of the different countries that allow medical assistance in dying.

So the Benelux countries do allow them, but they're tightly controlled. And so a couple of the countries out in Europe allow them only after an individual has been rendered unconscious and there is no chance of recovery. And that's when the Advanced Care Directive can kick in. The Netherlands has a bit more of a free approach to advance care directives insofar as they allow them and they have been used. But there have been problems with their administration. And so sometimes you can hear these horror stories that come out. And that's what causes this hesitation, right, is that you have these advanced care directives, but there are obviously sometimes issues that come out of it. And so, what do we do then?

And so those are things that Parliament grapples with and sometimes the understanding in the general population about what these advanced care directives can do is different from how Parliament actually sees them working in law. And so it relies on expert opinions. It relies on various things like the Canadian Council of Academies, to go forward and appoint a bunch of practitioners and academics from across a plethora of different faculties and organizations to try and study these issues to come forward.

But it's also an issue that doesn't have this clear cut answer for everybody. How I think advanced care directives should be used is different from how somebody else should think advanced care directives should be used. And so it's sort of becoming this issue where there isn't a right answer. And so we have to figure out a way forward.

David - Dr. Brennan, one of the questions I often ask our expert contributors to these conversations on behalf of our listeners is the question of what can a listener do about their thoughts around medical assistance in dying? How can they participate perhaps in the debate either on Bill C-7 or on the issues that remain outstanding, and especially as it pertains to advanced directives, or advanced requests, rather, that are specific of concern to people with dementia.

Dr. Brennan - I think that's such a great question, because one of the great things about this law is that it has been shaped by Canadians, right? In terms of the fact that it's been Canadians that have pushed the agenda.

And so we see this idea of a really huge role for the general population involved in it. And so there are typically public consultations that have taken place. You can also write letters and contact your Member of Parliament and signal your concerns about the legislation or going forward.

There are also lots of different non-governmental organizations who are actively involved in pursuing this area. And so you can get involved with non-governmental organizations.

Last but not least, if you find that you yourself are unfairly impacted by the law, there is always litigation, and that means that you can, in fact, challenge the laws in court. And there are organizations that help do that. And so we have and we've seen the B.C. Civil Liberties Association, for one, being a huge proponent of medical assistance in dying, they are the ones who helped bring forward the Carter case. They also brought forward a case challenging Bill C-14 called Lamb and that has been recently been dismissed. But there are these organizations who helped litigate these issues. And so if you've contacted Members of Parliament, if you've been involved in organizations and you still find that the law isn't changing, we have avenues to force change, which is through the court system.

David - Very interesting that you should mention that last piece, because that certainly would be a dramatic and effective tool for people that feels strongly about a particular aspect of the legislation or its application in an individual person's life.

And I really want to thank you very much for agreeing to participate in the discussion, for the way in which you clearly outlined the issues that were originally captured in a Bill C-14, the efforts to try and fill some of the holes and correct some of the practical problems in that original legislation, and especially your advice to people in terms of moving ahead.

Our resource page contains material outlining Bill C-7 and how it proposes to change the current regime. We have also included statements from the Alzheimer Society of Canada and from Dementia Advocacy Canada. Please check this out by visiting our web page www.dementiadiologue.ca

Both the statements by the Alzheimer Society and Dementia Advocacy Canada have struggled to respect the positions of both people that may prefer MAID and those that think that think otherwise.

You might also want to check out in a specific way the video clip that is connected to our resource page, called A National Conversation by the Canadian Broadcasting Corporation.

You may want to get involved and I would suggest that you do so by writing your MP and expressing your views on Bill C-7 and by contacting the Alzheimer Society of Canada or Dementia Advocacy Canada to express your thoughts on Bill C-7 and also to follow the advice by Professor Brennan.

Let us know what you think of this episode or if you have suggestions for other episodes.

Please remember to subscribe to our podcast on any of your preferred podcast platforms. Or you may wish to continue by going to our website.

At this point, I would like to express our continued appreciation to the Center for Education and Research on Aging and Health at Lakehead University, the sponsor for this program.

Thank you very much for listening and I look forward to sharing with you another episode in the near future.

Please consider writing to us at dementiadiologue@lakeheadu.ca

You can follow us on Twitter and also on Facebook. Thank you very much. My name is David Harvey.