Taking care: Choice and person-centred dying

Transcript

TASH:
Before we start, a quick note that today's episode is about the serious topic of death and has mentions of suicide. If this might be triggering for you, then we advise listening with caution and it may not be appropriate for younger listeners. Ahpra acknowledges the Traditional Owners of Country throughout Australia and the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures, and Elders past, present and emerging. Welcome to Taking Care, a podcast of Ahpra and the national boards. I'm Tash Miles. Together, there are many difficult issues that we grapple with, and one of those is death and how we die. Today's episode is about VAD or Voluntary Assisted Dying and what the realities of legalising VAD for doctors, patients and our broader communities has been. Victoria was the first Australian state to pass VAD laws coming into effect in 2019, and this discussion is a reflection on what this has meant for patient safety and choice in dying. What challenges have arisen and what the future could and should hold Joining me are three guests who each have important involvement in this work. They are general practitioner, Dr Nola Maxfield, oncologist Dr Cameron McLaren and Andrew Denton, who wears many hats, but perhaps the most relevant to this discussion is that he is a TV and podcast presenter and producer, and founder and director of Go Gentle Australia. Nola, could you tell us a bit about yourself and your interest in voluntary assisted dying?

NOLA:
Yes, for the last 36 years I've been working as a rural doctor in Wonthaggi and the Bass Coast area, and that has involved providing cradle to grave medicine, as they say, including the full spectrum of GP, obstetrics, anaesthetics and emergency care, along with palliative care and residential aged care. So caring for people at the end of their life has always been part of what I've done and what I've tried to ensure can be as good, as good a death as possible for the people and the family involved. And so, once voluntary assisted dying became legal in Victoria and they were looking for someone to provide that service within our area, I decided that I would do the training and be involved.

TASH:
And Cam could you tell us a bit about yourself and your involvement in voluntary assisted dying.

CAMERON:
So I'm Dr Cam McLaren. I'm an oncologist in South East Melbourne. I originally got involved with voluntary assisted dying because I thought it was going to be a very normal progression of what we do in terms of patient-centred care. I mean, voluntary assisted dying came in because of patient and community demand for it, and we as doctors are there to provide education and guidance with regards to medical decisions that are made by patients. We are not there to make decisions for patients or create the path for the patients, we're there to educate and walk with them. So I did the training the night before it went live on the naive understanding that I think I thought it was what we were all going to do, that there weren't that many of us who were stepping up to it, and there were a lot of patients whose needs and wishes were not being able to be met. So I then offered my services to see patients more broadly from other doctors and from the patient navigators. And so, very quickly became one of the more experienced voluntary assisted dying assessment providers in Victoria.

TASH:
And I think that we'll return to this, the importance of patient-centred care again in this conversation. Andrew, could you introduce yourself please.

ANDREW:
I guess I'm here as a representative of the person lying in the bed, the person being treated. I've had extensive experiences of that, having had heart surgery and various operations, and I've being blessed with brilliant family GPs all my life. So, I have a lot of respect for and affinity with, as a patient, the medical profession. I got involved with this specifically as a result of doing a lot of research for the first podcast series I made called Better Off Dead, back in 2016, and I spent a lot of time talking to doctors and nurses and specialists in Australia and also overseas about this subject, and I spent a lot of time since looking and speaking to people in the medical profession about voluntary assisted dying. And you mentioned and Cam mention patient-centred care, what I've discerned is there's quite a debate within the medical community about what patient-centred care actually means, and the pointiest end of that is voluntary assisted dying. I've seen a wide range of responses to it from the deeply engaged people like Cam and Nola, to the deeply oppositional. And I guess through that prism is the overarching question for the medical profession, when it comes to end of life care, what are our responsibilities and how much do we trust the person in the bed to know what it is they want for themselves?

TASH:
Thanks, Andrew. And yeah, we hope this conversation will start to explore some of those responsibilities. Death is a difficult topic. Nola, why is it important that we talk about it?

NOLA:
Sometimes it is only with the doctor that people will feel confident in talking about death. That may be a topic that is not able to be raised within their family or with their friends, and for other people, it's quite easy to talk about, but for many people, it's not. And I think we need to give them permission to be able to talk about that. I think we have to be honest with our patients, and I do see people who get what I would call futile care because people haven't had that discussion and we need to respect the patient's wishes. They need to know that they're approaching the end of their life so that they can then make decisions on what they need to do, what they would like to do in the last part of their life. If there's anything they need to finish off, what they would like to say to the family and friends. And I think that we can't deny them that. I think that's part of the care we should provide.

TASH:
Cam, could you comment on the difficult conversations that you have and still keeping a patient focus, even when the patient is dying.

CAMERON:
Oh, yeah. Look, we have difficult conversations every day in oncology, and it can range from, I'm sorry, but I think we need chemotherapy to avoid your cancer from coming back, to look, your incurable cancer has progressed and we need to talk about next line chemo or to things like, the cancer is doing what it wants, no matter what we do and it's now come the time where we need to talk about whether more treatment is in your best interests. And it really comes down to the art of medicine, and that's really why I chose oncology in the first place, as I thought it was a wonderful balance between the art and the fantastic science that there is in regards to cancer medicine as well. People remember 10% of what you say and 90% of how you say it, and so, tackling those difficult conversations is incredibly important, as Nola said, to frame the rest of the patient's life, to help them achieve their goals, give them a timeframe and an expectation to how well they're going to be during however long they've got. I think it's important that we have upfront discussions and we don't shy away from the difficult discussions.

TASH:
And so now we've got this situation for a couple of years now in Victoria, where voluntary assisted dying is legal, it is possible. I wonder, Andrew, could you tell us what this means for health practitioners and for members of the public, now that that is legal in Victoria?

ANDREW:
Well, I think the best way to answer that is to talk about why the law was necessary. A significant parliamentary inquiry heard evidence. I think there were 17 days of public hearings and over a thousand submissions, one of the biggest public inquiries ever held in Victoria. And what came out of that was, what the committee found was that there were repeated examples of doctors not giving sufficient pain relief at the end of life for fear of prosecution. That families were having to, and people who were dying, were having to suffer through long, drawn-out deaths by refusing nutrition and hydration. Because that was what the law allowed, that terminally ill people with suiciding because they felt they had no good pathway. There was no medical pathway left to them. And so, the summary of all of this was that people at the end of the life and their families watching on who were in that critical situation where they might choose VAD,

were completely disempowered. They felt disempowered. And I have spoken to and seen many, many testimonies of people in the medical system at the end of life, literally begging for more pain relief. This person needs more pain relief and being told we can't do that or after the event being told, look, that's normal for dying. You don't really know what you saw or kind of a gaslighting going on. To me, VAD law is about power and I don't mean that in a brut sense, but I mean it in terms of if you're at the end of your life and you run out of medical options before VAD laws, you had very little power in the system. One of the testimonies to the, that committee, was from an intensivist in Victoria, Professor Charlie Cork. There was a tiny nugget in there I took. At Barwon Hospital, we've done a survey of all the medical notes to see how often what the patient was thinking had been mentioned, and I think it was in less than five per cent of those notes. So this is about reversing what, the power of the doctrine of double effect and it's not just about what the doctor intends, it's about what the person in the bed also intends and needs.

TASH:
Two things Andrew, the doctor you just mentioned, Doctor Charlie Cork was in our previous episode about VAD, so that's a good reminder to check that out after this episode. And also, could you tell us what is the doctrine of double?

ANDREW:
This goes back to St Thomas Aquinas and this was, you know, it has its value, certainly in the medical profession. What it says is essentially that a doctor can give as much pain relief as necessary to relieve pain, even if the unintended consequence is to hasten a patient's death. But they must never give that amount of pain relief if they intend to hasten the patient's death. Now, of course, you know there are doctors who have very strong religious beliefs to who believe that this should be a natural process, you know, actually quite a lot of the medical system is built on that belief. So the ultimate effect of that can be for doctors who hold that belief, that don't want to do anything that might hasten the patient's death, is they may give the necessary drugs more slowly. And I've certainly, I've interviewed a senior palliative care physician here in Sydney, at St Vincent's, who actually said that to me. If I can't help you, if I can't help you with your pain, I'll help you live with your pain. So that's an example of, as Marshall Perron, the man that passed the first voluntary law in Australia, back in the 90s in the Northern Territory, said to me, this debate is about who has the keys to the medicine cabinet. And the doctrine of double effect that, if you like, codifies that it's the doctor who has the keys.

TASH:
So we hear about hastening death. Cam, does it actually happen? What do you see around you?

CAMERON:
Outside of voluntary assisted dying, yeah, I think it absolutely does. Intentionally or unintentionally, this has been happening as part of standard terminal care in hospitals for longer than I've been a doctor. Absolutely, and, you know, this is my introduction to palliative care as an intern was that, you know, the doctor would double the syringe driver every day and that was considered standard palliative care. And that's not what palliative care is, but that, you know, that kind of process of hastening death and not wanting patients to linger in a state of pain and purgatory. The intent there is certainly, I would like to think, coming from a compassionate place. But the way that we've been practising end of life care has been highly variable and highly unregulated, and the introduction of a law such as voluntary assisted dying gives a structure. It gives a way of monitoring what we do and it gives a mechanism of how to do it that is reliable, that is safe and is also patient-centred and above the table. You know, we all know what we're doing and it's no longer behind closed doors or nudge-nudge, wink-wink medicine.

TASH:
And so Nola, is that what you see around you. Is the reality that this law has made these changes?

NOLA:
Yes, I think it gives the control back to the patient and previously, it was all held by the doctor, as has been said, and it was really a lottery as to which doctor you ended up with and what sort of treatment they gave you. But it will still involve the doctor making decisions on what was valuable and what was going to give the effect the patient wanted. So I think it's great to actually have this out in the open. The patient then has the option on falling back on it if they want to. Not everyone's going to take it, but just to know that it's there, can give people a lot of peace of mind.

TASH:
And Andrew, what does this mean for a patient's support network like their friends, their family?

ANDREW:
It means many things. I've had the privilege of speaking to a number of families that have now been through this law. It means on the one hand, they don't have to watch the person they love suffer. And that's hugely important because the trauma caused by that is enormous but it means, on the other hand, there's a slightly surreal experience of farewelling a person on a designated day and at a designated time, and that's extremely difficult. And, you know, one of the core issues when this law is debated, as it should be, is, well, how do you write a law so that people who shouldn't be eligible aren't coerced into ending their lives? What the Victorian experience has shown is, in fact, that coercion is all the other way. It's families not wanting people to do this and that emotional pressure, and, look, voluntary assisted dying is humane and merciful and long overdue and much demanded, much required in Australia, but it's still not a golden ticket. You still have to die, and I don't know anyone that thinks dying is an easy thing to do.

TASH:
In your experience, what has the uptake been, Cam, from patients?

CAMERON:
So the uptake of voluntary assisted dying has certainly been greater than what was expected or predicted in, before it came in. I think, looking at models from other jurisdictions, it does tend to work at around .2 to .4 of the yearly deaths in any jurisdiction, in the first year, That then escalates at a rate over the next few years to level out at about, you know, in Canada, it's around 4 per cent of their yearly deaths. In Oregon, it's far less than that. So it really is jurisdiction and culture-dependent about what the ultimate uptake is going to be like. But I think if we look at that .2 to .4 per cent in the first year, that's actually where, exactly where the first year's applicants actually came out as. The uptake from it, on an individual level, I think people have really found it gives them a lot of comfort in terms of receiving the medication. There's that there is a real palliative effect of receiving this medication or even having wishes respected. And, you know, often when we, when I see patients, some of them are very close to the end of their life and I know that we're not going to have a good chance of getting through the application process because that does take a significant amount of time. But people still feel validated and heard, and it is palliative to go through the process anyway. It's been, the biggest thing I think I've found is that when receiving the medication, people are able to then not worry. People at this stage of their chronic illnesses, and most of them are cancer patients, very few of them are scared of dying. They've grown accustomed to that since the day they were first diagnosed when they first heard the C-word. What they're not sure of and what they're worried about is how that's going to happen. What receiving this medication gives them is comfort in knowing that if their worst fears are about to be realised, they have another option. And so, they get the medication they have it in the cupboard and they save it for a really, really rainy day. And if that really, really rainy day never happens and they die a natural death through palliative care, then that's fantastic. But they don't have to worry about their worst fears coming true anymore. It's had a huge effect on the anxiety around the end of life and I think also, on the patient's families who see them go through that. They help them achieve something in terms of the application process. and, you know, this is mum's wish and I'm helping her, and I'm being there for her, and I'm contributing to that. It gives them something to do. It gives them something to help them work towards. So it gives them a lot of validation in terms of helping that person in that phase of their life. So I think it has a profound effect on the people around them as well.

TASH:
Nola, I'd be keen to hear whether what Cam said resonates with you and your experience with your patients.

NOLA:
Yes, definitely. For people in rural areas, sometimes it's difficult for them to actually get the necessary paperwork done. You know, they've got to have two doctors and just accessing those two from a rural community can be really difficult for people and if it's late in their disease process, sometimes we're actually not able to get through the process in time and sometimes they're dying not in the way that they had thought. And I know with one situation, somebody who had worked out exactly where he wanted to be and on his property, and he had it all arranged. Who is going to be there, what was going to happen, but unfortunately, we couldn't get the voluntary assisted dying process done in time, and we didn't quite achieve that, but he almost achieved what he wanted. And yes, I think it does help the family. It means people have been able to be honest in front of their relatives about what they want and I find that's been very good for me to be able to facilitate that as part of the whole process.

CAMERON:
I'm conducting a PhD into that effect, actually, is the effect of voluntary assisted dying involvement on the grief and bereavement process. That's how much I suspect this is having a significant impact in the grief

process. So I haven't got any results yet, but what I've embarked upon is looking at essentially the prevalence of what is now referred to as prolonged grief disorder, which is a new entity in the DSM-5.

TASH:
What's DSM-5?

CAMERON:
It's essentially the diagnostic coding from a psychological perspective regarding things like major depressive disorder, generalised anxiety disorder, and it actually gives us a structured diagnosis to these conditions. And so previously, things like major depressive disorder, post-traumatic stress disorder, generalised anxiety disorder, they all existed and were able to be studied in populations. As of last year, prolonged grief disorder is now a separate entity, which has a bit of overlap between some of those, but is its own specific diagnosis now. And we're actually able to assess that in some populations. So we're only just looking at what the prevalence of that is in the general population, in the general bereaved population. And my question is really, well, what's the effect of being exposed to a voluntary assisted dying death on that prevalence? We know that being exposed to a traumatic death such as a suicide death, leads to greater risk of things like post-traumatic stress disorder and elements that are now considered to be part of prolonged grief disorder. But I think one of the main points that we all talk about as people who are involved in voluntary assisted dying is that none of us believe that voluntary assisted dying is suicide.

TASH:
Because I guess some people associate VAD with suicide.

CAMERON:
And I think this is going to be one of the ways that differentiates it from suicide, is that the effect and the outcome, the long term effects are completely different. One is going to be very negative and I've got a feeling that one is going to be quite positive because of the, what VAD provides a patient and their family. And, now it's been mentioned just before, is that it gives these gives patients and their family a moment in time where they know that everything that needs to be said, must be said by that, by that point in time. And people can't then say, oh, not today. I'll talk about that with them tomorrow or there's one last thing that I want them to say, but I'm not ready to talk about it with them yet, and then they missed that opportunity. Voluntary assisted dying gives a definite moment in time where those things need to be said by us. So it allows for those stones to be unturned. So my theory, my hypothesis is that through that, it is going to lead to a reduced prevalence of prolonged grief disorder in family members of people who engage in voluntary assisted dying. I'm in the early stages of the research at the moment and haven't got any results to prove that, but that should come in, in the next few years.

TASH:
And Andrew, you've had lots of conversations with patients, family, people involved or not involved with that anecdotally, does this resonate with you? What Cam's hypothesising?

ANDREW:
Massively, but not without exception. So massively in that going back to what that Victorian inquiry found, the trauma felt by families of not being able to help someone who was in extreme distress was terrible and at its worst, if that person suicided, and all suicides are terrible and many of these were terrible beyond measure. Any improvement on that is a vast improvement. But in fact, the experience of talking to most people whose family members have been through VAD is they are... it was such an act of love to help their family member to this ultimate moment. The deepest act of love you can ever express, in many ways, is to let someone go when they have to go, even though you don't want to lose them. I see in many ways VAD has a profound expression of love, but that hasn't been universal. You know, that old Tolstoy thing about every happy family is happy in the same way, and every unhappy family is unhappy in their own way. Well, not all families are happy and, you know, I spoke to one family who, the wife of the man who used VAD is a doctor and does assess for VAD, supported his choice. The whole family did, but having gone through it, they were very stricken by the experience, and I think their children wonder if they did the right thing, so, even though they understood and supported their father's choice. So, with what I was saying before, death is a profoundly unsettling experience, no matter which way you cut it. But in the mean, voluntary assisted dying is absolutely, is everything that palliative care does and aims to do, and does so admirably, which is to help people live as well as they can, while they die. If it's you who's dying, you want your family's last memories of you to be as close as possible to the person they loved, not some torn up shell of a human being begging for mercy, and that's what voluntary assisted dying has made possible for those, that extreme level or for those who don't wish to go down the palliative care pathway. I'm saying that very specifically, it is one of the things that concerns me about this debate. I think palliative

care is hugely important, but it is not mandatory. It's not mandatory in this legislation, and no medical treatment in Australia is mandatory, and I think we sometimes can overemphasise the palliative care pathway. Not everybody wants that. Not everybody needs that.

TASH:
If you're enjoying this episode, first of all, sorry for taking you away from it quickly, but I just wanted to let you know that we have another episode on VAD and here's a brief snippet from Dr Charlie Corke.

CHARLIE:
Personally, I just feel a little more relief that medicine is not turning its back on a reality of life and death.

TASH:
Be sure to check out that episode and all the rest of ours, by searching for Taking Care in your podcast player. And let's get back to Nola, Cam and Andrew. Nola, what would, as voluntary assisted dying was becoming legal, were there any challenges that you anticipated and have they been realised or have there been new ones?

NOLA:
I have. One of the challenges I found was actually when doing the training, even though I was supportive of the whole process that I did find it personally confronting because it actually made me think about issues. I guess, even though I have dealt with them in many ways over the years and been certainly upset at the fact that I could not provide what some of my patients wanted. You know, over all the years, you always had people who were saying, well, you know, I don't want to suffer at the end, can you end it for me? And we always have to say, well, no, we can't do that. It's not legal. So I welcome the legislation, found that personally difficult, on the training, but then once I started doing it, I found that it was such a profound service to the patients and their families, that it was no longer difficult. It was... it's not something you'd say you enjoyed, but it was professionally rewarding to be able to provide that for them. I guess, as part of the legislation, I find it difficult that I can't raise the issue with patients. That's a Victorian specific issue in the legislation, and I don't like the fact that somebody is telling me that I can't offer the full suite of what is available to my patients, that I rely on them having to know about it. And for some people, they may not know about it. They may have not heard of what's happening. There might be language difficulties, other barriers to that. So that's something I found difficult as well. And for my rural patients, accessing the two doctors and getting that all through, has sometimes been difficult.

TASH:
It sounds like there are access levels in terms of information awareness and also physical geographical access as well. Cam, what about you? What challenges, I guess, A, did you anticipate and B, have emerged?

CAMERON:
I think absolutely, it's a confronting thing to do when talking about it at face value, I think the prospect of, particularly the practitioner administration, where we intravenously administer medication to end the life of the patient, is incredibly confronting when it's taken outside of that patient context. And so, the idea of doing that was very difficult to wrap my head around. Similar to Nola, I think when I started providing that service, it was for patients that I was assessing, obviously, and so, I'd get to know them and their motivations, their reasons for applying, what they'd gone through over the years with regards to their cancer journey, and when you put a face and a background story to it and you understand that next level of what you're providing this patient, and then, it does... I don't think it's easier, but it's less confronting. I'm not sure that that's explaining it well. But certainly, the idea of it is very hard to come to terms with. But when you put a patient face and story behind it, you really lean on that professional reward and understand that you're providing the patient with something. I don't think you're taking anything away because the cancer or the disease has already done that. They've, it's taken everything away from that patient. You're providing them control, you're providing them comfort and you're providing them support when they've been looking for support, you know, for, you know, for this purpose. In some cases for weeks or months and feeling like they've not been heard and, you know, you're actually validating that. So it's incredibly rewarding work. It's incredibly taxing work. I've just come off a month where I've asked for no referrals for the, for a month. I've been working quite hard for the last two years on providing voluntary assisted dying to a lot of Victoria, actually, seeing patients all over the state. And I don't think I realised how much of a toll it was taking at the time. And after having come up for air for a month, I think it certainly was. So I think we need more people trained to share that load. We need more doctors to take up this role. We need more doctors in rural areas to take up this challenging aspect. And there are other things that I think would make it easier. Things like the ability to use telehealth, which is a, is another area of

quite significant opposition and legal uncertainty. I think that would certainly improve access for, particularly some of Nola patients and other patients in rural areas. And I agree that there's a big divide in awareness with our patients about what's available and also, the understanding about what doctors can and can't say. I mean, the wording of that restriction is that the doctors, in the course of providing health care to a patient, must not initiate a conversation that is, in substance, about voluntary assisted dying. But it doesn't say that a patient must actually say voluntary assisted dying in order to raise the topic. So when patients actually say, can't you just end it? They've initiated a conversation that is in substance around voluntary assisted dying. And doctors, I think, need to be aware that, well, that's what that needs to be recognised as, and you don't have to tease that out of them, and you don't have to actually get the explicit words of, I want to apply for voluntary assisted dying, out of your patient, in order to then explore it a bit with them. And I don't think the education has been optimal amongst doctors, generally, and health care professionals, generally, outside of the formal education that is provided on an opt-in basis. So, people who undergo the training, I think, are educated reasonably well. But this is legislation that applies to every doctor, not just the ones who have done the training and many doctors have not been educated about what they can and can't talk about, or what the rules are here, and they're very worried about contravening laws that they haven't had explained to them. So, you know, then we're left with a difference of opinion with interpretation of these laws and a divide in terms of what should be occurring.

TASH:
So, Andrew, not all doctors have done the VAD training, which may mean that a patient needs to go to a doctor who isn't someone who they've had a therapeutic relationship with, they don't know them well. What does it mean for the patient that there are fewer practitioners who have this training?

ANDREW:
Interestingly, one of the doctors I interviewed for the podcast, who was Dr Peter Lange who runs the Acute Care Unit at Royal Melbourne, he said that even though they weren't all his patients and therefore, necessarily, the time with them was, might only be a matter of weeks. He said, because of the nature of the request, two things. He said it's actually improved my skills as a doctor in that, he said, I'm a bit ashamed to admit that when I would ask them about suffering, I would unconsciously lead them to talk about the things that I could treat. And I've now come to understand that suffering is a much broader context than perhaps I'd understood. But he also said, because of the intensity of that period that even though it might not be a long relationship, it's a very involved relationship. It is, for any doctor, a very big thing for someone to come to you and say, I have reached a point where I want to have control over the prospect of ending my own life. Can you help me? And I don't think there is any doctor, no matter how long they've been in the business, no matter how many people they might have seen die on their watch, who doesn't take that as a profound request. So, I guess that's my way of saying, you know, it would be ideal if we had a system like the Netherlands where essentially your GP is with you, with you, all your life. That's kind of how their system works, but we don't have that for different historical reason. So, you know, one of the concerns, when this law was debated, was a thing called doctor shopping where some, I don't know how this was ever going to work, but some poor, terminally ill person would not find a doctor who would find them eligible. So they would just keep travelling around until they found a doctor who did, as if you've got nothing better to do when you are grievously ill. In fact, the reverse is proven to be true. People have to go to and doctor shop, unfortunately, because there's so few doctors that will do this, and the most disturbing example I've heard of this, under the law, if you have a neurological disease, you have to have two specialists confirm that you have less than 12 months to live. And there was a woman called Helen Gibb, who had Motor Neurone Disease, who lived in the centre of Melbourne, so right in the middle of all those hospitals, and thankfully, her GP was involved with the process and did all the legwork. But to get that second neurological confirmation that she had 12 months or less to live, it didn't even require any of these specialists to be involved in the process other than to go, yes, we think that's a fair prognosis. They had to approach three different specialists. It took six months for a dying woman who was in great fear and a terrible story in the end. And I can only echo what Cam and Nola are saying. I understand why there are many reasons why doctors are reluctant or concerned about getting involved. Certainly, conscientious objection is an entirely valid reason never to get involved. But I think there are many doctors who maybe haven't considered this. I've been surprised. It surprised me. Two things really surprised me. One is I didn't realise that doctors aren't naturally good at death and dying. I just assumed that came with the territory. But they're human too. None of us really like to face it full on. And the second thing is, and I still see it. How little knowledge doctors have about these laws, including many doctors who fiercely opposed them. They simply didn't educate themselves. And my sister-in-law lives in Melbourne, and she spoke to her family GP just in general about voluntary assisted dying, saying, you know, if the time came is this something you'd help me with. And her GP said, oh no, we don't kill our patients. And this gets back to the concept of patient-centred care. And I understand doctors have a huge range of responsibilities and this, you would think, would over a career maybe not come up many, many times, but nonetheless, it is, to

use that word again, perhaps the most profound thing that a doctor can be asked to do. I feel it is important that doctors educate themselves, and I have seen, and I truly believe, that the existence of this law and the very conversation that's been had now with medical professionals, who will go to other medical professionals, that the tide will rise. That a better conversation will arise within the medical community, not just about what the law is, but why is there a need for it? What does it mean when somebody asks you this? It doesn't always mean that this is what they're going to do or even this is what they need, or what they want. But it's a permissive law. It permits a conversation which was impossible to have before and it's a very necessary conversation.

TASH:
Nola has this, has being involved in the VAD changed how you think about death as a practitioner, as a GP?

NOLA:
I think it's added an extra dimension to how I think about it and can involve it, in work. I've seen many deaths over the time and you certainly do reflect back, but I do feel that this has increased my ability to deal with it and think about it in ways that don't take me somewhere that I would not be within the letter of the law, and I think that's valuable, in that part of it.

TASH:
What should the future look like for this VAD landscape, in order for it to be more, even more patient-centred? You know, we've had this law in place for a couple of years, and we've, obviously, there's a bunch of things that we've learnt. What should change, Cam?

CAMERON:
I just wanted to touch on the requirement for a specialist in Victoria because this is something that other jurisdictions have successfully avoided. So, you know, I think sometimes is seen to be a weakening of their act. But to me as a strengthening in their access. So what I think is important is that, as an example, in Victoria, in 2020, there were 6,600 plus GPs registered, compared to 265 oncologists. So if we're asking voluntary assisted dying assessments, 50% of those, to be performed by a comparatively much smaller proportion of doctors, I think that's just poor workforce planning. And the benefit of involving a specialist in the application, really is in the prognostication. That's really what a specialist is there for, to make sure that the patient is informed about all of their treatment options and a reliable, well, as reliable as can be, prognosis is given to that patient, but that doesn't need to be done by an assessing doctor. Two non-specialist doctors can use the information provided to them by a specialist to find that patient eligible. So I think that's been a real problem within Victoria, particularly for oncologists such as myself and has led to me being involved in over 150 cases of application of voluntary assisted dying. Whereas most GPs have been involved in half a dozen, you know, at most, that would be quite an experienced, relatively experienced GP. At the moment, there is a real clustering of the assessment provision amongst the specialists. So I think it's, it's very important that, I think that, that difference is appreciated in terms of workforce availability. Interestingly, also, I think in the same period there was around 220 neurologists and about 190 haematologists. So, regardless of speciality that's involved, it's really quite difficult to obtain a specialist who's willing to provide a VAD assessment, who's done the training and then, when the patient requires a home visit, you know, specialists don't do home visits as a rule. Specialists sit in ivory towers and the patients come to them. GP's do home visits, and that's what many patients need. So it's also very hard to find a VAD trained specialist who will do home visits and then one who will also provide practitioner administration, also, then becomes an even rarer breed. So you can see how those requirements have led to a significant strain on those of us who are providing the assessments at a speciality level.

NOLA:
I would hope that once the legislation is reviewed and the time comes to do that, there will actually be some changes made to make it easier for everybody who is involved. And I would certainly like to see more GPs do the training and become involved. But it's, as Cam has mentioned, it does take a toll emotionally and it can be difficult to fit into busy schedules. It does take time to go through this with people, and also, you do it more for love than for money. So sometimes it's the financial issues weigh more with some doctors than others, and that's not really been addressed in the provision of this service. So, much as I dislike to talk about money, it can also be a barrier for doctors getting involved.

TASH:
Andrew?

ANDREW:
Well, I think the first thing is, and Cam has spoken about this, it requires more doctors to get engaged, and I'm going to give a shout out to health professionals for Assisted Dying Choice, which is a group of health professionals around Australia that support these laws. For medical professionals who may be listening, who thought, well, I haven't given this a lot of thought, but maybe this is something that I, in principle, agree with. Please go there. So it requires more doctors to sign up and educate themselves, as I said, about the need for the laws. I think things like telehealth clearly need to change. Unfortunately, that's a federal law, and it's going to require the federal parliament to change the law there, to exclude voluntary assisted dying from a definition of suicide, which is what that law is supposed to be about. It's the conversation now within the medical community. You know, in the course of my research, I interviewed a fabulous senior palliative care leader called Molly Carlile, who is deeply oppositional to these laws. She came from a strongly Catholic background, both personally and in her training, with that view of natural death, and felt that, yes, palliative care can really deal with everything, taking into account terminal sedation. But a couple of things started to challenge her thinking and she sat herself down and said, why am I so oppositional to this? And she came to a point, which I thought was very principled. How can we say we believe in patient-centred care, and we support your choices as a patient, except the ones we don't agree with? And she said, I felt that was being hypocritical. And so, she has moved. She's on the implementation, she's on the Voluntary Assisted Dying panel for Victoria and I find that deeply principled. I do accept that there are doctors with a strong conscientious objection and I strongly support their right not to be involved. But I think there are many other doctors who, health professionals, perhaps, who are caught in what I would describe as an old way of thinking, that doctor knows best and I would urge them humbly to look more carefully at what is happening with voluntary assisted dying and what it has meant for the doctors involved and what it has meant for the people involved, the families involved and the people dying. And while I understand those who cite do no harm as their reasons for not getting involved. I think it is also a very deep expression of doing no harm to help somebody who can't be helped in any other way, through voluntary assisted dying.

TASH:
Well, thank you and that wraps up this conversation, Nola, Cam and Andrew. So thanks for taking the time to navigate a difficult and emotional space, but, obviously, an important one. We appreciate very much the work that you do beyond conversations like this. Work that guides meaningful change with a person-centred approach. Thank you.

ANDREW:
Thank you, Tash.

NOLA:
Thank you, Tash, for this discussion.

CAMERON:
Thanks Tash.

TASH:
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