

Taking care: The law and patient choice at the end-of-life

Transcript

SUSAN BIGGAR:

AHPRA acknowledges the traditional owners of country throughout Australia, and their continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and elders past, present and emerging. Today's episode contains serious themes of death and suicide. We advise listening with caution if these events may be triggering for you, and it may not be appropriate for younger listeners. Welcome to Taking Care, a podcast of AHPRA and the national boards. I'm Susan Biggar. Today, we're talking about a topic that affects all of us, eventually. It's death, and what the law has to say about it. The law in Australia has changed in several states in the past two years regarding voluntary assisted dying. Now, we know this is a sensitive and a complex topic, but fortunately, we have two eminently qualified guests here with us today to talk about it. I'll begin with Dr Charlie Corke, who is Deputy Chair of the Voluntary Assisted Dying Review Board, with the VAD board in Victoria. We also have Dr Scott Blackwell, chair of the VAD Board in Western Australia. Welcome to you both. Can I begin with you, Charlie? Can you tell us a bit about yourself and your connection to voluntary assisted dying?

DR CHARLIE CORKE:

I'm an intensive care specialist. I've been practising for many, many years, and I've for a long time been a strong advocate for patient-centred care guided by what patients want, and it's very clear to me that patients want voluntary assisted dying. Now, surveys show overwhelming support, with over 80% of people supporting VAD legislation. I do realise that there will always be a minority who take a very different view. But because of the vast majority who see this in a positive way now, I'm very comfortable to be in a position to try to support it.

SUSAN BIGGAR:

And Scott, can you describe your own background and how you ended up in voluntary assisted dying?

DR SCOTT BLACKWELL:

I come from the other end of medicine. I'm a generalist. I'm a GP. For many years, I was in the mainstream broad spectrum of general practice, but for the last 25 years or more, I've been more and more involved with palliative care. And so, I've really come from a palliative care background to this. But I guess it was a little bit of a wake-up moment when I had a call from the minister to say, would I be on the expert panel when they were putting the legislation together? And I really had to question myself because I hadn't actually been either an advocate or an opponent to this particular entity in our lives. And so, my instant response was, Yes, Minister, I'll do that.

SUSAN BIGGAR:

Good answer.

DR SCOTT BLACKWELL:

My involvement sort of emerged. But like Charlie, I think one thing that's been very compelling was the very broad community consultation that we did during the ministerial expert panel days. It really showed very dramatically that the people of Western Australia really wanted this.

It is - that 80% that shows up in the surveys is actually quite right when you get out there and talk to the people.

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SUSAN BIGGAR:

Well, Charlie, maybe can you define that voluntary assisted dying for us and what it means for health practitioners?

DR CHARLIE CORKE:

OK, well, voluntary assisted dying is a clearly defined legislated process that permits patients with a terminal illness to legally obtain medication that will peacefully end their life in a way that they value and in a way that they can avoid things that they really don't want to want to avoid. That's how I see it. And I think the situation for doctors is really interesting. I mean, in a survey that we did in my hospital just before the Act was implemented, we found that the overwhelming majority of doctors agreed that the Act was a good thing. And that was really similar to the rest of the population. Now, doctors are normal people. And they also said that they'd support a family member who wanted to take this route. So again, unsurprising normal behaviour. But most of them were hesitant when it came to being involved with the process. And that's, you know, involved in their professional role. And that's really interesting because it obviously doesn't sit easily for many doctors with their perception of their medical obligation to prolong life and to save life and to cure. And so, that's obviously really important. But having said that, there are lots of doctors who feel that this is something that they really should be involved with. And I think we do talk about conscientious objectors, but I'm also recognising that as a conscientious provider, people who feel that as part of their medical practice this is something they should be providing for their patients.

SUSAN BIGGAR:

That's interesting. So it's sort of like as humans, they think it's a good idea. As doctors, they're a little bit more uncertain about it.

DR CHARLIE CORKE:

Yes, I think our medical training makes it somewhat difficult. And I think that really comes into play, and Scott would probably be able to talk about this a bit more when we come to palliative care because it's clearly quite confronting to some people in palliative care and completely logical to others.

SUSAN BIGGAR:

Scott, do you want to comment on that?

DR SCOTT BLACKWELL:

Yeah, I think firstly, I guess defining voluntary assisted dying, I think Charlie has done a very good explanation of that. And I would just add the fact that to me, it really is one extra choice in the end of life pathway, and it's a relatively small choice although it has a very big impression upon the public psyche and on medical psyches as well, I guess. And for health practitioners, I see that's probably two challenges here. The first is, what if somebody sits down in front of me and says, "I want to access voluntary assisted dying." That's a big challenge. The other is, in fact, that will I be involved, or won't I, from implementation. Here, we're seeing the numbers growing of who are doing the training and the numbers are growing of who are willing to actually participate.

It's still a relatively small number, as it was in Victoria at the beginning. More and more, I think, will actually think about this and actually make their decisions. And in the end, I think, quite rightly, they are just another somewhat qualified member of the community, really.

SUSAN BIGGAR:

OK, so it's very, very early days in West Australia?

DR SCOTT BLACKWELL:

It is very early days. Here in Perth, you know, it's quite a sensitive moment and a respectful one this week because on 26 July, just over three weeks from implementation, the first person died from taking a voluntary assisted dying substance in the state. So it is quite an interesting moment here.

SUSAN BIGGAR:

Can you give us an overview, Scott, of the VAD law in Western Australia?

DR SCOTT BLACKWELL:

What it really means is something quite simple, really. It means that if you fit certain eligibility criteria, you have to be 18 years of age, a West Australian citizen, and so on and so forth. And you have to have capacity all the way through. And these things that are similar in both legislations, that you now have a choice if you are within six months of the end of your life, except if it's a neurodegenerative disease, within

12 months of the end of your life, you have the choice to be able to apply to end your life by taking the voluntary assisted dying substance. And then you enter the process of making an application for this, the first request as it's officially called. And then you go through a process that will probably take two or three weeks or so before you then receive a prescription. And then the voluntary assisted dying substance is either taken early or, you know, given by the medical practitioner. So essentially, that's really what the process is. It's just simply that extra choice at the end of life to avoid suffering that you don't want to actually face.

SUSAN BIGGAR:

Thank you, so that's the law in Western Australia. And Charlie, maybe you could tell us where there might be - are there any points of difference between that and the law in Victoria?

DR CHARLIE CORKE:

Well, there are a few little differences between the first law in Victoria and how the Western Australians are doing it. The first one comes at, our permit comes from the secretary of the health department. So, the doctor applies for a permit and the permit comes from a bureaucratic position in the health department. We're also, within Victoria, banned from raising the topic. So, although Scott says it's one of the options, it's not an option unless the patient knows about it. And I think that, you know, our legislators thought that doctors would potentially coerce patients by suggesting it and have undue influence. But the effect has been, rather, that doctors are very scared to respond to a request because they think it's something they can't talk about. And certainly, my junior doctors that I've spoken to about how they would respond, they're basically horrified and would just change the subject and try and get out of it rather than responding to patients as, "This is a response. They've asked me, and I should respond." So, I think that that's something that the Western Australians have noticed and have left out.

And also, I believe in Western Australia, a conscientious objection is OK, but if you conscientious object, you're required to refer and give the patient information about the process, which again in Victoria, that was specifically left out. And that's left us with a little bit - we do hear from patients and patients' families complaints that they've really been stonewalled and have found it very difficult to get listened to in the early stages until they've found access to a doctor, usually through the care navigator, to help them get the process started. So, and I'm not sure - that's one of the things I worry about in our legislation, that perhaps the balance is too far towards respect for objection rather than respect for patients.

DR SCOTT BLACKWELL:

We had a great advantage in that Victoria had done this before us. And in actual fact, one of our great advantages is that they've been so helpful to us. And a number of the differences that Charlie's actually referred to are probably because we talked to them. We are very grateful to having a big brother go before us.

DR CHARLIE CORKE:

I mean, although we've come first, we'll also have the opportunity of seeing how things work as these new models or different models happen across Western Australia and Tasmania and Queensland and elsewhere. We'll be able to have a look at that. And I think in five years we will be making some suggestions. I think by then we'll have proved that the process is safe and robust and we will have the experience of the other states, which will be good.

SUSAN BIGGAR:

Scott, what does that board in Western Australia do?

DR SCOTT BLACKWELL:

Essentially, the voluntary assisted dying board is a review board. It oversees the process. It watches the step by step process for each person to make sure that the process is being followed according to the law. That's really important. The second thing it will do, obviously, we're very early days, that's collect a significant amount of information to be able to advise government and the parliament when report time comes about a, how it's working, and b, how it might work better. And I think that they're really important things. We learned a bit from the Victorian board as well, and we have an extra step in terms of the first request and the need for doctors in Western Australia to actually register a first request, even if they aren't going to go through with supporting the person with that request. So, we're collecting that information, which will give us a very clear piece of data about, you know, how many people do make that request and not go on and so on and so forth. So, I think that's one thing that we built in at the Victorian board's suggestion. But overall, you know, we don't give permission, we don't take permission away, we don't look

at the detail of every case, but we look at the process for every case and make sure that every box is ticked.

SUSAN BIGGAR:

So the outcome of this process may well be a death, a voluntary assisted death. Charlie, it seems that this makes it particularly important that it's done correctly. Can you tell us about some of the safeguards that you as the VAD board are involved with?

DR CHARLIE CORKE:

Well, we're asking ourselves about the disease, the prognosis, we're asking ourselves about evidence of, you know, to be sure that there is no evidence of coercion, looking for competency, we're looking to see that all of the forms are done properly, that their witnessing is done properly by the appropriate people and not done by people who shouldn't be doing it, that the doctors signed in all the right places, that the dates are - I mean, because we have a very bureaucratic system in Victoria. Now, we want to make sure all the dates are right, all the names are right, all the dates of birth are right, all the dates, that things happen, they're right, that they're in the right order. There's an enormous amount of things when you look at it in that way. SUSAN BIGGAR: Have you had cases, Charlie, that you - where people SUSAN BIGGAR: Have you had cases, Charlie, that you - where people weren't able to access the voluntary assisted dying, that you were frustrated by that? Oh yes. I mean, we also see lots of patients who don't manage to get to the end of it, and Scott will recognise this as well. I mean, because we have the six months that patients are... That the doctor needs to certify that the patient, they believe the patient will die in six months. Not that they're likely to or could, but they will. That means that they are generally quite conservative about that. And often, patients die - by the time that they get onto the process, they're quite well advanced with their disease, and the process does take a number of weeks to get through the process. And a lot of patients die before they get to the end of the process. And each of the steps has inevitable time to complete, and as Scott said, the three day processing of every form that comes in. And then, of course, those are working days as well. So, nothing happens at the weekend. And patients, there's something interesting about the process in that clearly trying to get through this process is something that patients value at the end of their life. It's something about control, and they really want it and their families, you know, it's a thing that their families work with them as the patient's last wish they wanted to get through. And when they don't manage to get through, there's a feeling of failure, and we've sort of introduced that, I think, into the process where we don't get through it. So, that's a shame. And certainly, we get feedback from the family, which we get for - we try and get for all the cases and, you know, of great disappointment that they failed.

SUSAN BIGGAR:

It's the sense from families that they had a poor death and they might have had otherwise?

DR CHARLIE CORKE:

That's right. Or at least they didn't achieve something that they wanted. So, we get feedback from both the contact, the family as the contact person and from the doctor. And we're asking both of them, was that process reasonable or was it, you know, was not what you expected, something disappointing?

SUSAN BIGGAR:

Does it often match up, you know, if the families are disappointed or the other or frustrated? Are the practitioners often the same?

DR CHARLIE CORKE:

Absolutely. They're in it together.

SUSAN BIGGAR:

Charlie, I'm sure as an ICU doctor over decades, you have experienced many patient deaths. Has your involvement with VAD changed the way you feel about death? DR CHARLIE CORKE: I don't think so because I think - I mean, DR CHARLIE CORKE: I don't think so because I think - I mean, I think this is all - the thing is, this has always been there. It's just that it's now legislated and it's now sort of inside the tent rather than outside. It's always been outside the tent. People have taken medication or done things to themselves. And certainly, in our review when the ministerial review was being done, you know, the coroner gave a lot of examples of patients who had killed themselves, often in quite gruesome ways, reaching out for, you know, a solution. So, it's not like it never happened. It was happening. Personally, I just feel a little more relief that medicine is not turning its back on a reality of life and death. Yeah, I think it's a reasonable place to be. If patient choice at the end of life is something you're keen to hear more

about, you would definitely want to tune in to our next podcast. We have three stellar guests with extraordinary knowledge and experience. Here's Andrew Denton.

ANDREW DENTON:

Now that voluntary assisted dying is legal in Victoria, I've seen a wide range of responses to it, from the deep engaged to the deeply oppositional. And I guess through that prism is the overarching question: 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?

SUSAN BIGGAR:

If you enjoyed that teaser, then make sure you subscribe to Taking Care so you don't miss out on that episode. But in the meantime, let's get back to Scott Blackwell and Charlie Corke. And what's it been like to be involved in starting up a service from scratch, Scott? What's the process like in WA?

DR SCOTT BLACKWELL:

We've come through the implementation process, which was really quite exciting in a way because we had a very good crew working on the different strains of work, and the output was very good. It's probably my best experience of working with a team of people ever in my life, and the outcome has been really good. The training program is superb, and I think that also has a lot of safeguards in it that the people - we know that the people who are actually filling the roles in voluntary assisted dying are in fact well trained and know. And we've been able to work into that the whole scope of good end of life care as I've known it and practised it for a long time. The scope of the fact that families need to be thought about, we need to think of everything from the diagnosis to the suffering of the person to the grieving of the family. And we've included all of that in the training programs so that, you know, one of the leading questions is through that assessment process. are there members of the family who might suffer as a result of your choice? Should we be thinking about them and what their needs might be? And these are - so I think we've not just created something that's just separate from end of life care. It's something that is really part of that full broad spectrum of the whole of mankind thinking. Palliative care and all end of life care has been very much connected with the person. And as Charlie started off, that I've always been a person-centred person, which is music to my ears.

SUSAN BIGGAR:

Scott, I know it's early days in Western Australia, but have you had much feedback from patients and families about the scheme?

DR SCOTT BLACKWELL:

Yeah, I've had a lot of people approach me and talk to me privately. People have been waiting for this legislation because they've been very much in, you know, of a mind that this is something that they wanted to access. And I think at this stage, it is at that very early stage where people, I think, are relieved that at last, they have this choice to be able to avoid suffering that in many senses doesn't have any sense. And that if they can avoid that, then this is a good thing in their lives. And I think that's been the main response so far. We'll look forward to sort of the in-depth responses from the people who have access to it as we get to know them down the track.

SUSAN BIGGAR:

I'm sure that both of you, in the long careers that you've had, would have seen or heard of many deaths that were not good. That people or their families would have wished had gone a different way.

DR SCOTT BLACKWELL:

Certainly, I have in palliative care, and I'm sure Charlie is the same. But I guess for me, that sort of fits into two groups. And there's been the people that we've looked after in palliative care where we really haven't been able to manage their suffering in that global sense of suffering of the body, mind and spirit. And we've seen some pretty unpleasant experiences. And the other is, people in palliative care commit suicide more often than people who are not in palliative care. It's a statistical fact. And people do get frustrated with the fact that they're still here and they're still suffering and that palliative care just isn't enough for them. And we've seen and witnessed, yeah, unpleasant experiences over time, over 20, 30 years or so in palliative care, that you would wish had had another option.

DR CHARLIE CORKE:

In the lead up to the introduction of this, there was a lot of talk about, you know, how this was going to undermine palliative care and that patients were not going to get to palliative care because they take this route. And our experience has been that the vast majority of patients are actually under palliative care.

They actually like palliative care. They value palliative care and they're pleased about it, but they just don't like the end of it. And the idea of control, you know, it really does seem to be very compatible with great palliative care. And it doesn't seem to me to be as threatening. And certainly, for our patients, it doesn't seem to be this or that at all. So, this position of palliative care that it can have nothing to do with voluntary assisted dying, I think it is... Personally, I think it's probably a mistake. I think that. And the other thing I've come to see, that that's an especially important part of the doctor-patient relationship. The idea that it destroys the doctor-patient relationship, I think, is upside down. And what we're seeing in feedback is that refusal, when a patient reaches out and asks for this and they get a refusal, that seems like a terrible abandonment of what may well have been a very good long term doctor-patient relationship. And just at the point where the patient's really reaching out, they get rejected. And it starkly contrasts with the suggestion by those who oppose VAD.

But responding to a request would destroy trust, and they mustn't have anything to do with voluntary assisted dying because it would destroy the doctor-patient relationship and doctor-patient trust. It just seems upside down, and our feedback from patients suggests that it is pretty, it is upside down.

SUSAN BIGGAR:

And that maybe, as Scott said, anyway, this is actually just an option for people. That sometimes presumably people don't end up taking.

DR CHARLIE CORKE:

Oh, look, nobody's saying everybody has to have voluntary assisted dying, for heaven's sake. The thing that I think is a massive success is when the patient gets the medication, sticks it on the top of their cupboard, and leaves it there and never takes it because they never get to the point where they want to have it. But the feedback, again, from that process is that it's immensely reassuring to have it. And I think one of the things I feel badly about in our process in Victoria is, a lot of patients are getting it and taking it within 24 hours of it arriving. And they're going, "Get it here, get it here, get it here." Whereas it seems to me to be more reasonable if you can just get it and then have it for a bit and just take it when you're ready, not when you're desperate for it. And that thing about just having it, it's an insurance policy and it just gives peace of mind. And starting too late when patients are already fighting and there's the worry, "Will I be able to swallow it? Will it get to me - by the time it comes, will I have lost capacity? Will I have lost the ability to swallow?" It's all that worry. Whereas if it could get there earlier and just be there, it'll be, you know, that peace of mind is something that I think is really, really important.

SUSAN BIGGAR:

And truly person-centred in the sense of them, as you say, them needing to have control, some sense of control over their life and their future. So Charlie, why do you think we don't have many doctors wanting to do the voluntary assisted dying training?

DR CHARLIE CORKE:

There's a lot of factors. The first thing is, this is hard work. It's really hard on top of busy work to do this. There's a great commitment to the family and to the bureaucratic form feeling. If you say to doctors, "Would you like to do more form filling?" None of them will put their hand up. So, just being involved in it is complex and it's work. It's not - no one's in this for the money. It's a big commitment to do it. There are, of course, a number of doctors who are conscientiously objecting and will always be conscientiously objecting. But they're a small minority. The vast majority of doctors are just a little bit uncomfortable. We've got this thing about, you could get into trouble for APRA, you could get into trouble from the law. You know, you could be charged, you may get told by the department that you've done the forms wrong. You know, nobody really wants any of this. So, I think it's all those little things that add together. But hopefully, the value to patients is such that that will recede and it can still be safe but navigable. And I think we need to respect doctors' time and not make it unnecessarily difficult.

SUSAN BIGGAR:

Well, that's actually a nice segue into asking both of you, what do you hope to see in the next few years? What do you hope to see in the next five years? And what would a really safe and patient-centred system look like for you? Why don't we start with you, Scott?

DR SCOTT BLACKWELL:

I think because we're very much at the beginning, I think, and we've learnt so much in the last three years leading up to the legislation and in the implementation process. What I want to see in the next five years is us really learn now what's really right, you know? We've had an ability to predict it, we've put it into law, and now we want to really see how it really does work and then have the opportunity to readjust and say,

Well, if we go back to where this came from, and let's face it, this was the will of the people, that government decided to give them legislation for that, we've now implemented. Let's take that back and say, does this really fit with the will of the people? And how can we make it do that? That, for me, would be what I'd like to actually see in the next five years. It is the ability to do that.

SUSAN BIGGAR:
Charlie, how about you?

DR CHARLIE CORKE:
I'd particularly like to see VAD become a more routine and unsurprising thing. And actually, I think that's already happening in Victoria. I'd certainly like to see many more doctors become involved because the way that patients want this to happen is that you talk to your doctor about it. You see your doctor, the doctor you trust, the doctor that knows you. And part of the security of this and part of the safeguards is seeing someone who understands you. I don't think that the politicians were thinking about you going to see a completely different doctor. They thought that you would ask your own doctor and a number of them would be conscientious objectors and you'd need to make some other arrangements. I don't think they really anticipated that there would only be a handful doing this. And part of the thing about patients having to go and see a completely new doctor at this time is, I don't think, what the politicians wanted. I don't think it's what patients want and I don't think it's the safest thing, and I don't think it's a part of good medicine to start again with somebody else at that time. So, I'd love to see lots more doctors do it and just see it as part of their just routine practice. You don't do it very often, but when you are asked, it's part of what you do. And there's lots of things in medicine that we don't do very often but when we are asked, we do them.

SUSAN BIGGAR:
Well, thank you, Scott and Charlie, for helping us steer through what is, well, for many of us, I think, a tricky and a challenging topic, not only because of our personal connection to the reality of dying but also, I think, because of the complexity and ethical challenges about decisions at end of life and who makes them. We're really - we're grateful for your commitment and your care on behalf of patients and families, so thank you.

DR CHARLIE CORKE:
Thank you, too.

DR SCOTT BLACKWELL:
Yes, and thanks, Susan. I think I think it's been an opportunity for us to express a side of us that we speak of in private often, and this is a little more public, but I think it is something that we hope other doctors will reflect on and actually see what their place in the end of life care is, and specifically in voluntary assisted dying.

SUSAN BIGGAR:
So, we've talked about some challenging themes in today's episode. If this has raised issues for you, there is help available, for example, Beyond Blue or Lifeline. The contact details are available in our show notes. Thank you for listening to Taking Care. Please don't forget to find us on Spotify, Apple Podcasts, or wherever you listen to your podcasts by searching for Taking Care. You can subscribe, you can review, you can listen to our growing back catalogue. And if you have any feedback or ideas for future episodes, please drop us a line at communications@ahpra.gov.au, and we'll see you next time.