

Joan Kirner Social Justice Oration

Communities in Control Conference Melbourne, Tuesday, May 30, 2017

An address on assisted dying laws by

Andrew Denton

Australian media innovator and producer, in conversation with:

Virginia Trioli

Award-winning journalist and TV presenter (Watch this as a video | Listen here)

About the oration:

"Everyone is entitled to a healthy death!" However good our public health care, however careful we are of our diet, however low the road toll falls, the all-causes death rate is, eventually, 100%. However far off the horizon looks for you now, we'll all have to go through that vanishing point, and we should all take an interest in the boundary conditions. We die as we live: in society, bound by rules, enmeshed in politics. Let's talk it all through. It's the biggest social justice issue of your life.

A warning: Some people may find the content of this address disturbing.

Anyone with personal problems can contact <u>Lifeline</u> on 131 114, <u>Mensline Australia</u> on 1300 789 978, <u>Beyond Blue</u> on 1300 22 4636 or the <u>Victorian Statewide Suicide Helpline</u> on 1300 651 251.

Andrew Denton

I would like to acknowledge that not everybody in this room agrees with these laws and some feel very strongly that they shouldn't exist.

And I deeply respect that view, particularly if it's a moral or a religious view. I very much respect your right to hold that view. I disagree that you should impose that view on everybody else.

I would like to apologise, as some of what I'm going to tell you today is very hard to listen to and in my experience whenever I talk about it, it stirs ghosts in the room. There are people, I have no doubt, sitting here today that have stories which will chime with some of the stories you're going to hear, and I apologise if they cause further distress, but this is an issue that we can no longer look away from. We have to look it squarely in the eye.

How did I get to be here? One of the lowest examples of humanity that could possibly exist, a two-time failed Logie nominee, how do I get to be talking about this subject? From watching my own father die: badly, in pain, 20 years ago. Helped in the only way that people can still be helped. Allegedly the morphine was upped to ease the pain, but over those three days it didn't ease his pain and it didn't ease ours, and I will never forget the most profoundly shocking thing I ever saw, which was that three days. And as I speak to you now I see my father's face.

It wasn't at that moment. I was in my late 30s when I thought we should have a law for assisted dying. Like most people in that situation, like most families, we were traumatised. It happened, we got on with our lives, we buried my father.

It wasn't until many years later I read an article in *The Monthly* magazine by an Australian writer called Margaretta Pos, and her father Hugo was Dutch, where they have a law for euthanasia. And he was dying of cancer, and she was invited over for his final week. A date had been set where the doctors were going to come and with his consent end his life and his suffering.







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She described this extraordinarily civilised week where he farewelled his friends, where he rang his ex-wife and reconciled, where his children were around him, and when on his last night on earth all the big things had been said, they had a lovely family dinner. He spent his last night listening to Mozart, looking at the night sky, took a sleeping pill, got up early the next morning. Remember, this was a man dying of cancer, this was not a lifestyle choice as people like to paint it sometimes, and when the doctors came at the duly appointed time and he gave his consent this man, who was seriously ill, was humanely helped to die. And I contrasted my father's death with Margaretta's father's death and I asked myself: Why can't we have this law in Australia?

That was about two and a half years ago, and I didn't intend to end up on this path, but I've pretty much spent my time, full time, since then trying to answer that question. And in that time I have travelled around the world and around this country and spent thousands and thousands of hours talking with people on all sides of this equation.

The very first place I started was in fact an anti-euthanasia convention with speakers from all over the world in Adelaide, and I took very careful note of the very powerful arguments against, and I used those as my guide when I travelled overseas to the Netherlands and Belgium and twice to Oregon to measure up what I was being told against what I found.

In the end, I came to the strong conclusion that the reason we don't have this law in Australia is a very bad reason. It is, as I mentioned in that video (watch), it is a narrow but powerful group of people, a very paternalistic group of people, largely men, the heads of our religious organisations, many the heads of our medical organisations, who are deciding for personal beliefs that these laws are unacceptable. Very much against the evidence of how these laws work overseas, strongly against the evidence of the damage being caused in our own society, and deeply against the frequently and broadly expressed wishes of the Australian population.







So I decided, as I thought about this, I thought, you know you see street marches for pretty much everyone. But there's one group of people you never see marching in the streets and that's the terminally ill and the chronically ill. And why is that? Because they are our weakest and most vulnerable, and they are actually having the help that they so deeply request being denied to them by some of our most powerful organisations claiming to be protecting the vulnerable.

So I decided to set up an organisation called <u>Go Gentle Australia</u> to help be their voice and that's why that slide's up on the screen, or was up on the screen. If you could put it back there please I'd appreciate it. Because I want those of you who believe in this to also be their voice. And one of the first things we did was pull together this book called *The Damage Done* because I've noticed a common thread amongst those that oppose these laws, which is that they make the actual suffering in our community magically disappear when they argue against these laws. And this book is a collection of 72 testimonies. We pulled it together in just four weeks. We could have written twice this book easily, three times by now, from families, carers, patients, doctors, nurses, coroners, about the damage that is happening in our community because we don't have a law to assist people to die.

And I'd like to read to you just the introduction because it sets the scene for today. "As she was dying of cancer in 2015, 90-year-old Eileen Dawe kept a diary. Despite her clearly stated wish to die, she was forced to endure 17 painful weeks until the disease finally took her. Hoping to hasten nature's course she began to starve herself to death. In her diaries she wrote: 'My country's laws decree, death by a thousand cuts for me'."

Eileen's is one of 72 testimonies in this book that describe with horrifying clarity the damage being done across Australia in the absence of a law for assisted dying. Written by sons, daughters, husbands, wives, partners and friends, as well as the dying themselves, they detail trauma and suffering on a staggering scale.

The testimonies have come from people of all ages and walks of life. They represent almost every Australian state and territory. They are blue collar, white collar, devoutly religious, avowedly not.





The diseases they face are mostly cancer, but also multiple sclerosis, motor neurone disease, and other medical horrors. What brings them together is the cruel way in which they all suffered, or suffer still. With descriptions such as "akin to torture" and "like a horror movie", what strikes you about these testimonies is the repeated expressions from those left behind of shock, anger and helplessness, sometimes reaching back decades.

Some describe keeping grandchildren and children away from a cherished parent or aunt or grandfather because the dying was so hideous, so scarring. Talking about death is hard enough. Talking about bad deaths is even tougher. It takes courage. For many it means admitting to the terrible sense that they failed their loved ones. Perhaps bravest of all are the testimonies from doctors and nurses, some of whom have openly admitted to helping patients die. The trauma many of them have had to deal with in the face of their patients' suffering is palpable. May their example encourage others in the medical profession to come forward and speak openly about what they've seen and even what they do.

Had the abuses, cruelty and harm inflicted by our laws and so vividly captured in this book happened within one institution, we would long ago have had a royal commission. But because they've happened in many places, palliative care wards, nursing homes, general hospitals, people's houses, and because each has been a private tragedy they've been invisible, deniable, ignorable. This book is not intended as a critique of Australia's palliative care services or the dedicated doctors and nurses who give it their best. Rather it reveals what happens despite their best efforts.

In June 2016, a cross-party <u>Victorian Parliamentary Inquiry into end of life</u> <u>choices</u> reported on the evidence it had uncovered. The most extensive of its kind ever held in Australia, its findings, gathered over 10 months, mirror the anguished testimonies listed here of inadequate pain relief being delivered to dying patients for fear of breaking the law.







Of the inability of palliative care, despite its many benefits, to relieve all suffering. Of people being put on trial for helping those they love find a merciful end. Of doctors being forced to break the law in order to help their suffering patients die, but having to do so without support, regulation or accountability. And, of the trauma experienced by families as they watched their loved ones die harrowing deaths.

The testimony of <u>Victorian Coroner John Olle</u> in particular rocked the committee. Coroner Olle told of the horrific ways in which desperately ill Victorians are taking their own lives in order to end their suffering. This included a 90 year old man with prostate cancer who killed himself with a nail gun. Coroner Olle estimated these violent self-inflicted deaths are happening at the rate of one a week in Victoria. He went out of his way to emphasise that these people did not have a history of mental illness, that they came from loving families, and that they were beyond the help of palliative care.

Faced with such evidence the committee found that maintaining the status quo was unacceptable. By a majority of six to two, reflecting the 80 per cent support amongst the Australian public, they recommended a law for assisted dying be passed in Victoria. There's every reason to believe that the harm the committee found in Victoria is happening across Australia, and that it's not going to go away or get less. As our population ages it will only increase, and yet our politicians have declined to address it.

Over the last two decades now 30 attempts have been made in different state parliaments to pass a law. Only one has got to a stage where the detail of such a law could be debated, and the claim most commonly used to defeat it, that quote: "No safeguard can be devised to protect the vulnerable," has never been seriously examined, despite voluminous evidence from overseas that safeguards can, and do work.

The testimonies written in this book stand as a rebuke to this dereliction of duty. They ask serious questions of us as a society. After all, who could be more vulnerable and in need of protection, than a person who is dying?





Enough copies of this book have been printed to send to every state and federal politician in Australia. Should they continue to stand in the way of a law for assisted dying, they will do so in full knowledge of the suffering taking place in our community because of that refusal, suffering that will continue every week of every month of every year, until they act. The damage done. Who amongst our politicians has the courage to address it, and in so doing reflect the wishes of an overwhelming majority of Australians?'

Virginia, over to you.

Virginia Trioli

You spoke to us about the really difficult time that you and your family went through watching your father die, and you've spoken about that before. Many of us have been through that, have seen loved ones die a difficult death and even grappled with the issue of euthanasia, but we don't all become advocates like you have on this issue. What do you think it was that tipped you into that place and are you surprised at where you find yourself now?

Andrew Denton

Partly it was opportunity. I'd stepped out of the media and I was looking to do something that I felt had public good, and I keep files on lots of things. I'm like I guess the Kremlin, on things that interest me, and I went back to the one that I had on euthanasia and it was such a brilliant collision of moral, legal, ethical, all these things. So I decided to answer that question: Why can't we have this law in Australia?

What's moved me from a position of intellectual and personal inquiry to one of advocacy is what I've discovered along the way. This degree of suffering, what is happening in our suburbs every week. In the last three weeks, for example, these are two emails I've had from Victoria. One from a woman whose best friend is dying of cancer and who is invoking her legal right to hasten it in the only way she can, which is to starve herself to death, and what it is like to watch this happening. And the other from a nurse whose uncle, dying of cancer, set himself on fire in a car park.

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I keep hearing these stories, and I keep seeing on the other side how these stories are completely made invisible. Those that oppose these laws never refer to this. And so what has moved me to a position of advocacy is this strong sense, not just sense, this strong evidentiary realisation that there is a great social injustice happening in our country and there is a tragedy happening in our midst which could and should be addressed.

Virginia Trioli

You do see it strongly in terms of sides, don't you? That this is actually a strongly divided for and against issue in Australia. We'll stick with Australia for the moment.

Andrew Denton

Sure. Well, yes it is. Except those sides change. One of the testimonies in here comes from the family of Ken Dickson and he was, and they are, devout Christians who I'm sure did not believe in this law until they found Ken, who had prostate cancer, hanging on the clothes line. And he left a note, this tragic note, written on a "to do today" list saying, "I'm so sorry, I couldn't take this anymore". And the family collectively, I think there's seven of them, have signed their testimony in this book saying look, we're devout Christians but surely something can be done to help someone like our father dying of a terminal illness.

Virginia Trioli

So let's talk a little more about that entrenched group of, you said just before, mostly men, and powerful aligned voices who you say shut this discussion down and shut down any legislative change. Who are they?

Andrew Denton

It's two groups and they are, I guess, the definition of paternalism. At its core it's the church, but most particularly the Catholic Church, and that is because they have a core belief in the sanctity of human life, and that only God giveth and God taketh away the hours. A belief I respect. As I said, I have no issue with their belief. I have an issue with their imposition of it on everyone else.

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That view is expressed in various ways. First of all in perfectly straightforward democratic ways, in that they invoke their democratic right to encourage their congregations to write to MPs, as they're doing right now in Victoria, and they go and represent themselves to MPs as leaders of their denominations, as they're doing right now in Victoria.

But also in subtler ways, through groups that are affiliated with them that have been extremely good over the years at distorting the facts of this debate and spreading misinformation.

But there is another way in which religion expresses itself, and it's quite a hidden way, and it's actually the most effective way in this debate in that just under 60 percent of our palliative care in this country is actually provided by the Catholic Church. And they do a magnificent job; they are really good at what they do. But their very core belief handed down since the 13th century, St Thomas Aquinas, is we will not prolong nor hasten death. There is nothing they will do because it's against their belief to hasten the death of a patient, who they may not be able to help in any other way, and who by their own records might persistently and clearly request to have their death hastened. It is against their core beliefs to hasten it. So they present themselves as a medical argument, as in no, palliative care can take care of this, and nobody ever mentioned that it's actually their core Catholic belief that is driving the argument that they're making.

The other group, which is not necessarily religious, is the hierarchy of our medical bodies, most particularly the AMA. Now the AMA last year did a survey of its members on this issue, and reflecting similar medical organisations in countries where these laws exist, their membership was split almost 50/50 on this issue. Forty five per cent of doctors thought there should be a law. A third of them said if there was a law that they would assist a patient if so asked. Half of them said that they certainly believed assisted dying was good medical practice, and two thirds of them agreed with the proposition that palliative care could not always deal with the suffering of its patients.







So the correct position for the AMA to have taken to reflect their membership on this would have been that taken by their sister organisations overseas, which is a neutral position. But the AMA consistently uses its strong public platform to say doctors don't support these laws. And in the debate that just happened in Tasmania, and they did this in South Australia last year too, amongst the lines of attack that the AMA ran were, under this legislation what's to stop someone with acne being helped to die? Which is not only a load of specious bullshit, it completely steps past the actual suffering that people with cancer, serious illnesses, motor neurone disease, multiple sclerosis, it so trivialises that level of suffering. That's the kind of thing I'm talking about.

Virginia Trioli

I want to try and get into the mind of the doctors in just a moment, but let's go back a step to the religious organisations, and the Catholic Church in particular. I wonder if there might not be a moment that's needed in the debate, and I have no particular role or position that I take in this debate so I'll play devil's advocate, I don't know if it does your cause any good to keep saying things like "and I respect their view completely and I have no problem with that view", when it seems to me that you do.

Andrew Denton

I have a problem with their imposition of it on others.

Virginia Trioli

No, more than that. I suspect you actually deep down have a problem with the view of anyone being able to say - that anyone else or any belief system has control over the taking and the giving of life. We have abortion laws that are legalised in this country and therefore the logical end of that would be some kind of euthanasia law. To keep dancing on the head of a pin when you clearly do have, it seems to me, a problem with that proposition whether it be imposed or even just held within that tightly held group, I wonder if that's a little bit of bad faith and perhaps doesn't do your cause any good.

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Andrew Denton

Other people will judge if it does the cause good, but you misrepresent me. I do genuinely respect their view. There are people I've spoken to within this debate who strongly believe in the salvational value of suffering, who believe that we should suffer as we die, the example of Christ on the cross, and they are welcome to that. I really do not disapprove of that.

There's only one thing we know about dying Virginia, is that when we die it is our dying alone. We don't know how our dying's going to be and some people have deathbed conversions, some people go the other way. I do remember a palliative care nurse at St Vincent's Hospital in Sydney at 3 o'clock in the morning saying to me, people die pretty much as they've lived. If they've always been cantankerous, they die cantankerous. So no, I genuinely – if that is your belief when you die, because it is the single most autonomous thing we're ever going to do, die, we're only doing it on our own, I do support that. My issue is very much about the imposition of that belief on others, and our laws as they currently exist enforce the imposition of that belief.

Virginia Trioli

But I'm trying to get to the complexity of the paradox within that group of people who may even believe that too, who may be baptised as Catholics and live that way, and yet at the end of life find themselves in this position of wanting to be freed and released of suffering, but nonetheless understanding that this is the philosophy within which I have to live and have to die. So if that's the case and their suffering is somehow prolonged, you can't sit here and say nonetheless I respect that belief system, because that belief system is harmful to that person even if they are a Catholic.

Andrew Denton

But the point about these laws, the very key word, which is often skipped over, is that they're voluntary. So if someone doesn't believe in that, they have every right not to believe in that. That is the whole point.

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My issue is the way things currently exist, a narrow group of people are imposing their belief system on everyone else and in a very specific way. I'm not talking about a general philosophical point.

Let me explain how this plays out. Under our current law, in palliative care, and let me preface this by saying what I'm talking about hopefully is going to apply to very, very few people that you ever meet. The kind of people that this law would help is a small number of people, but very real. So under our current law in palliative care if you're suffering, and we'll talk about suffering later, not just pain, but suffering which can have lasted for a long, long time, can no longer be controlled by palliative care, they employ a thing called terminal sedation.

Now the figures on this are, from palliative care themselves - these are not made up, these are their own statistics - is that something like 7.5 percent of their patients who die, which is about 1300 people a year, our national road toll, have severe physical symptoms in their terminal stages. So they're the kind of people that would be terminally sedated. And what is terminal sedation? That's slowly, it's called titrating, drugging a patient into a coma from which they're never expected to awake. It's one of the things that palliative care say, "We've got powerful drugs at the end of life that can deal with all pain". It's a response to suffering and pain they haven't been able to control. It doesn't mean there's been no pain and suffering.

The point is, to get back to personal beliefs, under our law doctors have absolute right, unchallengeable right, to decide how much and at what speed they will give that pain relief. And I have spoken to, and read of, and I can give you testimonies of doctors whose strong religious belief is what the Pope says: There is value in suffering. Who talk about how wonderful it is that people can grow through their cancer. And this is a direct quote, I'm not making it up. And if that doctor with unfettered power, no matter the request of you the patient or the family, they decide how fast you are given that pain relief. And let me tell you a story and this is very shocking, and this is in Rodney Syme's book *A Time To Die*, and this happened right in the middle of your city.

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A man called Rudi Dobron, motor neurone disease, a shocking unpalliatiable disease invoked his legal right at the end of this disease to try and hasten it by stopping all food and fluids, and he was persuaded to go into a Catholic palliative care facility for palliation. In other words, to sedate him, to make sure that the worst of the suffering, which by the way when you're starving yourself to death and can take a long time is psychological, would at least be in some ways controlled.

Rodney Syme pulled the medical records through freedom of information of Rudi Dobron and in this Catholic care facility, despite a clear record of his psychological, physical and emotional suffering, was left for 32 days before he was fully sedated and it took him almost seven weeks to die. And as Rodney Syme said, this didn't happen in a desert. This happened in the middle of Melbourne with full facilities.

Now there is nothing in the law which said those doctors couldn't have sedated that man the minute he arrived, but they didn't. And our law gives doctors unfettered power to make that decision, and if your core belief is I'll never hasten death, or more than that, that suffering has virtue and that you will grow through your disease, then you can impose that belief as much as you like. And when the argument is made, as it is, and it's powerful to MPs, that all we have to do is give more resources to palliative care, it completely ignores the fact that you could give every resource in the world and if a doctor has this core religious belief then there's a limit to how much and how quickly they're going to help you.

Virginia Trioli

Leaving aside some doctors' religious beliefs as the second group that you talk about being strongly opposed to any change in the law, I wonder how much of some doctors' anxiety about it might be then also legal redress and responsibility and what might come to them later on and a lack of protection for them.

Andrew Denton

One of the things that's amazed me in this is that I hadn't realised, I'd assumed doctors were pretty good with death, but they're terrible at it. They're scared of it. They don't like talking about it. It's actually one of the big issues.





The Victorian Committee Report – it's been really interesting. I've never really gone into the granular detail of how a government works before and I've read a lot of these submissions and transcripts, and if there's one drum beat through all of it, it's that everybody's bad at talking about this subject.

The irony is that as the committee found, doctors are assisting patients to die right now but they are doing it without any protection at all. They're doing it without any consultation; they're doing it without any oversight. They're not able to talk to their colleagues; they're not able to get a second opinion. They're not able to do any of the things that the law that is being proposed will do.

And there is a deeper irony to this which is, when you think about it, the AMA's position for example arguing against this law, what they're actually saying is it's much better if our members just continue to break the law and we all turn a blind eye with no protection rather than that we give doctors protection, because this is why these laws exist overseas. These laws, nowhere do they legalise assisted suicide. They give a narrow set of criteria within which doctors can act to help dying patients. And if they follow that criteria, the doctors are protected from prosecution.

Virginia Trioli

I want to at some point, a little bit later we'll run through what the state of play is internationally. But when I dived into this subject because of our discussion today Andrew, it was fascinating to me, and I had no prior knowledge, that this discussion always breaks down, it seems to me, into a contest between palliative care and euthanasia. Has it historically always been thus?

Andrew Denton

In this country yes, and I think that's really tragic. I think the person that speaks best to it in this country, well there's two. One was a man called Clive Deverell. Clive Deverell, you may not have heard his name, but he started palliative care in Western Australia.





He was the first president of Palliative Care, and in the last couple of years Clive started to speak openly about the great tragedy that palliative care had become a weapon in this argument, and a weapon against these laws, when it was clear that within their own walls they have what he called "nightmare sessions" where they would talk about the patients they couldn't help. And it was clear that what was happening at the very end of life was being shut down, that conversation about it was being shut down. And Clive spoke about this publically in Western Australia as the former head of Palliative Care, so a pretty persuasive witness.

Clive himself had cancer, and on election day in Western Australia earlier this year Clive shot himself in a public toilet. And in the farewell note that he left, which was a long one to his family and it wasn't just about this, but it's relevant that he said this, he wrote that: "Suicide is legal, but euthanasia is not". Now that's a pretty powerful finger being pointed at his own organisation.

The other person that speaks powerfully to this is the father of Australian palliative care, the Emeritus Professor, Professor Ian Maddox, the first president of the Australian New Zealand Palliative association, who says that if helping someone who is dying with compassion and love is what palliative care is all about, then assisted dying is part of that, and it's time the profession embraced it. And he's consistently tried to build a bridge between those who advocate for these laws and palliative care, because the truth is assisted dying is the essence of palliation.

And the example of that happened, again in this very community, last year. Some of you may have seen an *Australian Story* featuring a man called Bernard Erica and Dr Rodney Syme. Bernard Erica was dying of tongue and throat cancer and as a result of *Australian Story* it became known that Dr Syme had offered, or had potentially offered, Bernard Erica, Nembutal, a drug that can peacefully end his life. And the Medical Board of Australia brought an action against Dr Rodney Syme ordering him to cease and desist from endangering the lives of his patients.







So Dr Syme did something he'd wanted to do for a long time. He took it to a public tribunal. He took it to the Victorian Civil and Administrative Tribunal who heard the case against him, heard Dr Syme's explanation, which was that deep psychological stress that this man faces in the event of his certain death and the suffering that lies ahead is what I'm trying to help him face, and in offering the provision of these drugs, it is not to offer him death. It is to help him deal with the remainder of his life.

They heard from Bernard Erica himself, who said in two submissions very clearly "no doctor has been able to offer me any comfort from the distress and anxiety I'm facing, knowing what lies ahead, until I met Dr Syme, and this has given me enormous comfort knowing that if this thing gets out of control, I don't want to die wired up on machines in palliative care. If this gets out of control, I can be in control of how things end".

And the tribunal in hearing this, and it was two doctors and a lawyer, and two palliative care physicians as expert advisors, made the following judgment. In fact I've brought it here because I hoped you might ask me about it, I want to get the words exactly right. They said: "Dr Syme is entirely focused on supporting the patient in life rather than pre-empting the patient's death". They also found the following in support of Dr Syme: "The right of any individual of sound mind to seek reassurance that they will be able to, if they wish, control the manner of their dying, the palliative effect on a patient knowing that they are dying and that the reassurance of the promise or the actual possession of the drug does not from the patient's perspective place them at any risk".

In other words, what they were saying is that this is palliative care. Because the people in palliative care, they have an incredibly hard job. Dying can be really complicated. It's on many levels. It's psychological, it's emotional, it's physical, it's psychic and they're trying to deal with all of these things. And all the people I spoke to in palliative care, including in Catholic palliative care who obviously don't support these laws, they all talked about two things. One, the bad deaths that they wish they could have done more for. And two, what's referred to as "existential suffering".





Now that's not a philosophical thing. Existential suffering is the actual pain and suffering that you feel at the core of your existence, which can happen as you're dying, which is many things. It's physical pain, it's loss of control, it's loss of independence, it's fatigue, it's the nature of the treatment, it's the side effects of treatment, it's nausea. It's so many things. I'm actually going to distress you if I go through it all, but it's the totality of all these things which is also known as total pain syndrome and that is the hardest thing they find to palliate. Yes, they can throw pain killers at you but it doesn't deal with all these things, and what that Bernard Erica case showed is that the offer of assisted dying is one effective way to help deal with existential suffering.

Virginia Trioli

I'm glad you spoke at length about that, because it seems to me, and again as an outsider to all of this, that palliative care and end of life discussion have more in common with each other than perhaps has been acknowledged. There's such a thing called a Flanders model that I've learnt about in the last little while where traditionally and historically those two aspects of end of life care, if you like for want of a better term, have always existed together.

Andrew Denton

That's exactly right, and in fact I spoke to the former head of palliative care in Flanders, a man called Arséne Mullie. It was a most unusual conversation. I was expecting to find this austere medico, and I found a man standing in a paddock full of cow manure in gumboots and shorts — who had emus. It was very bizarre, in Belgium.

But he was this beautiful man. I remember saying to him at the end of our conversation and lunch: "Arséne when I die I want you with me". And he talked about his philosophy of medical friendship. In palliative care, he said, it's so much more than medical, it's spiritual. The dying is a spiritual thing. He said there are times where I've lain with a patient who's dying for the whole night, I've lain alongside them.







And he said, but when it comes to a patient who is clearly dying and if there is nothing more to be done and if they express their wish for euthanasia, then how can we say no? How can we tell a patient who is suffering, "No, tomorrow you should suffer more"?

And so in Belgium, and in the Netherlands, and in Oregon it is understood that palliative care and assisted dying are the same thing. In Belgium three out of every four euthanasia deaths happen within palliative care. In Oregon, nine out of every ten of those deaths, those people are also in hospice care. These things are not apart, and that's why Clive Deverell was so sad that palliative care has been weaponised in fighting against these laws, when in fact they should be together.

Virginia Trioli

Our time is on the wing, so let me quickly put to you then a few misgivings that might be felt by either people in the room, or people in the community. The concept of a legalising of some kind of assisted death, I can imagine would be perhaps opposed by some, not for the religious reasons, or even the medical control reasons that you explained before, but perhaps for the same reason that many oppose capital punishment. Not that it's not warranted, but that we can get it wrong. Now how do we ensure that we don't get it wrong?

Andrew Denton

Okay, I guess what you've got to look at is: What is the law, and how do we know that it's worked safely overseas? And I'll try and make this as quick as I can. So the Victorian committee did what no other committee's done before in Australia, they travelled overseas to Switzerland, Canada, Oregon and the Netherlands.

Virginia Trioli

It's legal in four countries at the moment, isn't it?

Andrew Denton

More countries that that. In fact there's versions of it in Germany, in Columbia, Canada as well, I think I mentioned Canada.

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One in six Americans have access to this law, which when you think about it, being a religiously more conservative country than Australia, you think well how did that happen? It happened because they got a sensible law and it works.

Anyway, how did the committee come to this conclusion? There's a pyramid of things. First of all, there are a series of independent in-depth inquiries that have looked into these laws ahead of the Victorian committee, and the most series of those was in Canada. One went over two years in Quebec. Another one was done by a judge in the British Columbian court, where she brought in witnesses and affidavits from around the world, for and against, the most extensive and exhaustive review of all the evidence for and against. And she concluded in the end, that not only do safeguards work, but that there is no reason why a regime can't be designed in their country where safeguards work. That decision was appealed and then all that evidence was reviewed again by the Supreme Court of Canada who, unusually, unanimously decided in her favour and talked specifically about the voluminous and exhaustive evidence she'd gone through and that her conclusions were correct. So the Victorian committee started there.

And then on top of that, there is a literal mountain of academic peer-reviewed evidence. Because in the countries where these laws exist, they've made it their business to do what we don't do here, which is to put serious scrutiny on all their end of life decisions and care, so they know what doctors are doing. We don't know what our doctors are doing. And the overwhelming preponderance of this evidence supports that these laws are working, and working as they should be.

Then the committee went to these countries, and they spoke not just to people that support these laws but people against, and there they discovered the truth, that those who oppose these laws would rather you didn't realise, that these laws sit squarely in the centre of these societies. They were passed by clear majorities of their elected parliaments. The Dutch laws were both framed by and are still championed and used by the Royal Dutch Medical Society, their doctors. The Belgian laws came from within palliative care. These laws have massive public support. There's been no attempt to repeal them. The level of trust in doctors in all these societies is higher than it is in Australia.

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And on top of all of that evidence, is the reality that there's been no attempt made to repeal or pull these laws back by any of these societies. So we know that these laws work.

Virginia Trioli

Describe, if you can, the checks and balances. Describe a system and the way that it might work?

Andrew Denton

We still don't exactly what the legislation's going to be in Australia but we have a sense from the committee's recommendations. There's an expert panel now working on advice to the government, being led by the former head of the AMA, Brian Owler, but I'll put it this way. The most commonly used scenario as to why you can't have these laws is: "What's to stop the greedy relative coercing granny into putting up her hand to be assisted to die?" And that's a fair question. What is to stop them?

Well, let me explain how it works. First of all, this mythical granny has to make a verbal request to be assisted to die. Now under the laws as they're going to be proposed you have to have a serious and incurable condition and you have to be in the last — according to two independent doctors — in the last weeks or months of your life.

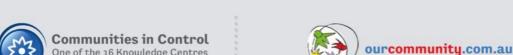
Virginia Trioli

And two doctors, they can determine that? Because as we know sometimes that can, that's mercurial, that's actually hard to pin that down.

Andrew Denton

Absolutely. Not all doctor prognoses are right. Interestingly, doctors tend to be more optimistic, research shows, rather than pessimistic. They tend to give a longer time frame than a shorter one, but remember these laws are voluntary. All a doctor has to do is make a diagnosis.

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Now we're talking about a serious and incurable condition. We're not talking about acne. The vast majority of people that access these laws, the overwhelming majority, 80-90 per cent, have cancer. Or it's motor neurone disease or it's multiple sclerosis. It's a serious disease. So when you front up to a doctor saying, "I want to access this law", you have to present with a serious disease. They are going to your medical records, they're going to your specialist. It's very, very difficult to coerce somebody into presenting a disease they don't have. And even more difficult to coerce two doctors — independent of each other — whose work will be open to review. Unlike now, where end of life decisions, there is no review. It is very difficult to coerce those doctors, with a disease that doesn't exist.

Virginia Trioli

And then, once the two doctors have established that we're at the end of times?

Andrew Denton

You have to make a verbal request. You then have to make a written request, which is witnessed by two independent witnesses, then another verbal request, and there has to be at least two weeks in between these. If then, both doctors agree - and if they have any concerns that it's a psychiatric thing that is driving your request they can refer you to a psychologist or a psychiatrist - they then, if they agree, the primary doctor, the first doctor you approach, can write a prescription for life ending medication. This is a drink that you and only you can take, which will end your life peacefully. It's the ultimate act of voluntariness, so only you in the end can take that drink.

Virginia Trioli

What if the doctors don't agree?

Andrew Denton

If the doctors don't agree, the primary doctor makes the call.

Virginia Trioli

And what if none of the doctors allow, for whatever reason they conclude, that patient to do what they want to do?





Andrew Denton

Then the request is declined. In the Netherlands, two thirds of requests are declined for many different reasons.

Virginia Trioli

And those people are palliated until they die?

Andrew Denton

Well, it depends. You see the very interesting thing in the Netherlands, going back to palliative care, is that a lot of people who make requests, upon making the request end up rescinding the request and going into palliative care. And this is one of the key things about it. As I said, the drumbeat that came through the committee as it spoke to your community over 10 months, is that these conversations are not being had. This is part of the reason suicides are happening, because there's nowhere to turn to. There's nowhere to have this conversation.

And the point about these laws, they are permissive laws and what they permit is a conversation between you and your doctor. And as the head of the Oregon Medical Association said to me, and they've had these laws for 20 years and the number of people that use them is less than half of one per cent of all the people that die every year, he's a doctor and he explained to me, he said, when a patient comes to you with a request for assistance to die, your first response is well, "let's see what we can do". Your first response is well: "Why would you make that request? What's happening in your life? What kind of treatment are you getting? What kind of support do you have? What's happening in your family life"?

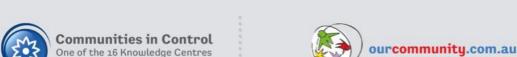
Doctors don't want to do this. Doctors are inherently conservative. To assist a patient to die is a very major thing for all people concerned. So the law mandates, as it's being proposed, that doctors must go through all treatment options with a patient.

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Virginia Trioli

Where are we then in terms of legislation in Australia right now?







of Our Community.

As we heard before from Denis, we've had one bill voted down in Tasmania and various goes elsewhere, South Australia most recently. And now we're looking at something potentially in Victoria.

Andrew Denton

I think Victoria by far represents the best chance. And that's why I was keen to come and talk today. Because different to every other state, where it's mostly been individual politicians or small groups of politicians that have put forward a bill, this is a bill that's been put forward by the government.

It's based on a committee that was led by a Liberal MLC, Ed O'Donohue, a cross-party inquiry that strongly supported the law by a strong majority, and which is being informed by an expert panel which includes senior palliative care physicians, nurses, the former Public Advocate and the former head of the AMA.

So there's enormous process and thought and consultation. Over the last four months, this panel has had meetings with 300 individuals across the medical community, informing how to write this law. So there's enormous process gone into it.

But do I think this law's going to pass, despite the clear case for it? Despite the amount of process and thought that's gone into it, the strong public demand for it, I think it's at best 50/50. And why is that? Because what I've discovered is that there is a serious flaw in the thinking of the public about this, which is that most people think it's a no-brainer we should have these laws, therefore they're going to be passed.

But those who strongly oppose it, and the Catholic Church are a prime example, are deeply organised against and they make sure, and they're doing it right now, that their congregations get in the faces of MPs. So for this law to pass in Victoria, and I know that there are MPs here from different parties, from all parties, and they will know this, it requires you to be heard. It requires you to actually activate yourselves. Go and speak to your MPs.

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I want to make this very clear. If this law doesn't pass in Victoria this year, it will be a long time before any such thing comes. And as I said in that introduction, and for every week and month and year that the law doesn't exist, these horrors will continue. And God forbid that they happen to you.

Virginia Trioli

We are out of time, and I just want to finish on something that is very important to me, I think, and should always be important and front and centre in public debate, and that's the role of doubt. And it keeps us from becoming ideologues and it keeps us from becoming oppressors I think. Is there no shred, no shadow of doubt in your mind about the potential dangers, the potential risks of a law like this? And if there is, can you speak to us about that?

Andrew Denton

I spoke to a man called Eric Wijlick from the Royal Dutch Medical Society, and this was fairly early in the process, and we were talking about the safeguards in their law and I said, "So that much pretty much guarantees that nothing bad will ever happen?" And to my surprise he said, "No, it doesn't guarantee against abuses. You can never have a perfect system. You can never assume that it will be perfect". But he said, "What we do know is that there is far more safety and scrutiny than existed before, when we didn't have these laws, when we didn't know what was going on".

So can I sit here, and should I ever say, hand on heart, "No it's impossible that something bad would happen under this law?" No. It would be ridiculous to make that proposition. But what I do know is the bad things that are happening now, and I believe they're inexcusable, they can be dealt with, and the real true bad things that are happening now far outweigh the possible hypothetical harm.

It is often said by MPs that vote against this, "Well look I can't vote for this law because what if something terrible happens down the track"? Well, I think that's a real abrogation of their duties. To actually turn away from these suicides, and these people starving themselves to death, and these clear testimonies of terrible deaths, based on something you're afraid might happen somewhere in the future which the evidence doesn't support from overseas, I think is a terrible dereliction.

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But if you want to talk about doubt, I'll finish by telling you this story. It's very brief, because I know you're looking at your watch. Jerry Brown, the governor of California, who trained to be a Jesuit priest. California was the second most recent state in America and its most populous to bring in these laws, and as the Governor he had to sign this into law and because of his Catholic faith he really struggled. And he spent two weeks talking to other priests, talking to representatives from the disability community, talking to families of those who had died. Talking to Archbishop Desmond Tutu, somebody's who's actually spoken very strongly that it is the Christian thing to assist people to die, and in the end he did sign this into law. This man with doubts. And he said this, and I think it was a deeply moral thing to say, he said, "In the end I do not know what I would do if I were dying in prolonged and excruciating pain, but I do know it would be a comfort to me to be afforded the options offered in this bill and I would not deny that right to others". And I think that is a great example of a man of religious faith, a man with doubts, that understood that this was the right thing to do.

Virginia Trioli

Ladies and gentlemen, Andrew Denton.

Andrew Denton

Thank you.

ENDS.

Anyone with personal problems can contact <u>Lifeline</u> on 131 114, <u>Mensline</u> <u>Australia</u> on 1300 789 978, <u>Beyond Blue</u> on 1300 22 4636 or the <u>Victorian</u> <u>Statewide Suicide Helpline</u> on 1300 651 251.





