

**MEDICO-LEGAL SOCIETY OF NSW INC.**

**SCIENTIFIC MEETING WEDNESDAY, 14 NOVEMBER 2018 AT 6.15 P.M.**

**TOPIC: 'Assisted Dying'**

**SPEAKERS: Ms Kate Gillman and Professor Brian Owler**

**MC & FACILITATOR: Dr David Gronow**

**Dr David Gronow:** Thank you very much for joining us this evening. I am David Gronow the President of the society and I welcome you all to another one of our scientific meetings, and this should be an interesting one on assisted dying. Just some housekeeping, could you please turn your phones on to silent, the club rules are that there are no phones in the club apart from in the phone booths or out in the street. So that also goes for dinner. So tonight, we have got two speakers talking on this subject and I am sure it is a very interesting and contemporary subject that will continue to produce a lot of discussion. So, hopefully from tonight you will have some facts to make the discussion worthwhile. So first to speak tonight is Kate Gillman, she is Head of Medico-Legal Advisory Service at Avant, and in this role Kate helps co-ordinate the 24-hour medico-legal advisory service for Avant's 65,000 members. Kate has over 20 years' experience as a solicitor and barrister representing and advising healthcare practitioners and hospitals in Australia, England and Singapore. This work has covered public, private and government sectors. So welcome Kate and we look forward to your presentation.

**Ms Kate Gillman:** Thank you David. The death of a parent is devastating for anyone and can have long enduring everlasting effects for the children of that parent. For one man, the memory of the pain his mother suffered in the last stages of her life endured and stayed with him for a number of years. Including on a skiing trip, a few years later to Oregon in the United States, where he read with keen interest about the proposed assisted dying legislation, that at that time Oregon was debating. That man of course was Marshall Perron, the then Chief Minister for the Northern Territory, who returned back to Darwin, where there is no snow I can assure you, and asked his Attorney General to look into introducing similar legislation here in the Northern Territory, thinking as he did at the moment how much different his mother's end stage of her life may have been had she had the option to take advantage of that type of legislation. I had moved to Darwin after I finished University to work as an associate with one of the Supreme Court Judges in 1991, then, to finish off my articles, moved across to the Attorney General's department in the Northern Territory and was working with the Solicitor General at the time. Depending on how you look at it, I was either in the right place at the right time, or in the wrong place at the wrong time, but nonetheless what I ended up doing was, I was involved in the consultation process for what was to become the Rights of the Terminally Ill Act in the Northern Territory. I distinctly remember a doctor looking at me over a table during this consultation phase asking me, 'How could I get up and look at myself in the mirror knowing that I was involved in this consultation phase?' And then on the same day, meeting with a patient who had terminal stomach cancer and intolerable pain who was asking me 'Why is it taking so long for this process to go through?' I didn't then, and I don't have now, a really strong view about assisted dying legislation, which is perhaps good for someone in my position: not having a really emotive position. But I guess what that experience left me with was a really strong understanding of how emotive the issue of assisted dying legislation is for both patients and for doctors.

So, as you know, the legislation did pass in the Northern Territory in 1995, it came into effect in July 1996 and four people died as a result of the legislation before Kevin Andrews put a bill, a private

members bill, before the Commonwealth Parliament and the legislation was overturned using the Commonwealth's Territory powers. And so here we are, rolling on over 20 years and where are we at? Some of you might be surprised to know that there have been fifteen attempts at legislating assisted dying legislation in South Australia, the last one was in November 2016 and as there was a 23/23 on both sides, the speaker had to have the casting vote. As you know, in NSW an attempt to legislate assisted dying failed last year. Brian is going to fill you in on some further developments that are occurring just at the moment as we speak in some of the other states. And also explain his role as a Chair of the Consultative Committee in Victoria.

Where we are at the moment is just over six months away from the Victorian Voluntary Assisted Dying Act coming into force on the 19<sup>th</sup> June next year. So, what I am going to do today is just really give you an overview of that legislation and the process to access Voluntary Assisted Dying in Victoria. I can say without a shadow of a doubt, the consultation process in Victoria was a Gold Standard as consultation goes. The document that was produced by that committee, which runs I think 250 pages, is an amazing document if you are interested in looking up the history of voluntary assisted dying around the world, it is a very good read. I was going to share with you a bit of a video but given our experience of video's last time I have decided not to risk it. What I was going to show you was a minute of the interview with Professor David Goodall, who some of you may have followed in the media recently, who decided to go to Switzerland to end his life. He was 104 years old, he didn't have a terminal illness. He basically ended his life having had spent time with his family and eating a meal of fish and chips and cheesecake and asked the question again 'why is this taking so long?' as he was waiting to die. My question I guess when I looked at the Victorian Legislation is, if Dr Goodall had decided to wait a bit longer could he have accessed assisted dying under the Victorian scheme? And I just thought I would take you through the key criteria for this scheme, and the reason I think it is important that we understand the Victorian model, because as Brian will let you know, this model is being looked at in other states and may well become the model for future legislation around the country.

So, at 104 Dr Goodall was clearly over 18 years old: 18 years old is the age in the American Legislation. Interestingly, in NSW they were proposing 25 years, not 18. In European countries, assisted dying is available to people under 18 years if they have continuous pain. In Victoria they have landed on 18 years. The benefit of having Brian here, is we can ask him questions as to why they have made these decisions. Professor Goodall was an Australian Citizen and Resident, as you know in some of the European countries there is no residency requirement. But here, there would have been his two hurdles. He was from WA so not ordinarily a resident in Victoria and had not lived in Victoria for the last twelve months. It is a double requirement, you have to be ordinarily a resident in Victoria and have resided in Victoria for the last twelve months. Which I think is to stop people from just moving to Victoria for twelve months. And over there on the bottom left hand side is, or your right-hand side, is what is required as criteria under the legislation. You have to have an incurable, advanced and progressive condition or illness that will cause your death and is likely to cause your death within weeks or months and a period not exceeding 6 months. You will see it is 6 or 12 months, it is 12 months if you have a neurodegenerative disease like Motor Neuron Disease. I haven't added it there, but the other criteria is that not only do you have that condition, but you are also suffering from a level of pain that for you is intolerable and cannot be relieved by pain relief that is tolerable to you. And that really is the defining feature of why this Victorian Legislation is probably, if you are talking about tough criteria, the toughest criteria in the world. In the United States, for example, there is a requirement for an incurable or terminal illness, in Europe there is not, but there is a requirement for intolerable pain. So effectively what the Victorians has done is combine the two criteria. If you had watched the video, I could have shown you, you would have

seen there is no doubt in anyone's mind Professor Goodall at 104 still had decision making capacity, which is one of the other criteria: that you have the capacity to make voluntary, non-coerced decision to seek assisted dying. Interestingly, under this legislation it is not mandatory to have a psychological assessment. That was going to be one of the requirements under the NSW legislation, but it is not in Victoria. I think I read somewhere that part of the reason was psychiatrists in Victoria didn't want to be the gatekeepers to assisted dying. The presence of a mental illness is not an automatic barrier to requesting assisted dying. If any of the doctors involved with the patient are uncertain about capacity, then they are required to get an assessment by a psychiatrist or psychologist as to that capacity. The test is the same test as in Victoria's new Medical Treatment Planning and Decisions Act that came into effect last year. So that gives you an overview as to what the criteria is, these are the steps, and you will see as we go through these steps how it is quite a vigorous process for those people who are worried about whether there are sufficient safe guards up under this legislation. You will start to get a feel for the number of safe guards or steps there are. The first request is you have to make the request to the doctor in person, and that doctor has to have gone through some approved training. The training modules, as I understand it, are still being developed by the Victorian Government, but it is a requirement before you undertake an assessment that you have undergone approved training, which is understanding the requirements under the legislation and the principles behind the Act. It is really interesting, but it is an offence under the legislation to initiate a discussion about voluntary assisted dying with the patient. So, you can't say "oh look you are having a bad day, have you thought about assisted dying?" that in itself would be an offence. And if your colleague, if you are a doctor in Victoria, and your colleague becomes aware that you have initiated such a discussion, under the legislation that constitutes a mandatory report for AHPRA purposes. So, it is quite a tough – it might be interesting to discuss, talk to Brian about – I have been trying to think about the logistics of this in terms of how patients actually identify doctors who might be able to assist them, if you are not allowed to initiate discussions. I'm not sure how it would fit under AHPRA's advertising guidelines. For example, so those logistical questions might – obviously in my role other sorts of things that we get asked and we start to think of in advance of any legislation like this. The doctor then has to accept or reject the request within 7 days. Interestingly again, under this legislation there is no duty on that doctor if they decide to reject the request for conscientious reasons if they conscientiously object, they don't have a positive duty to refer the patient to someone else who may be able to assist them. Now this is different in Victoria to the Termination Act, as is the case in QLD recently, in those cases doctors who have conscientious objections to abortion do have a duty to refer on to another doctor. That is not the case in this legislation. Assuming that doctor then accepts the request, someone agrees to be involved and they have done the approved training, they become the Coordinating Medical Practitioner under the legislation, that is their title, and their job is then to assess the eligibility – effectively go through the process I just went through, that criteria. There are lots of steps that doctor has to take, they have to fill in a form, they have to document it for discussion in the medical records, they then have to refer the patient on to what is called a Consulting Medical Practitioner, so Coordinating Medical Practitioner and Consulting Medical Practitioner. That doctor also has to accept or reject the referral within 7 days, and assess the patient's eligibility, essentially the same test. Now both of these doctors have to be fellows of a college, or a vocationally registered GP. At least one of them has to have 5 years post fellowship experience and at least one of them has to have specialist training in the patient's relevant medical condition. So, it could be one or the other. Both doctors have to provide information to the patient which is set out in the legislation, and briefly includes explaining the prognosis, the diagnosis, explaining palliative care options, treatment options, explaining that if we give you this medication it will cause your death and interestingly encouraging the patient to inform other doctors who might be involved with their care that they are

going through this assisted dying process. That doctor then has to complete a consulting assessment report, basically stating whether or not they consider that the patient is eligible or ineligible, they have to complete it either way. These reports have to be sent off to the Voluntary Assisted Dying Board, which is a statutory board which has been set up by the Victorian Government with oversight of this scheme. And then what happens? The patient goes back to the Coordinating Medical Practitioner, probably more likely to be the GP, the patient has to sign a written declaration confirming that they want to go ahead with their request, that has to be witnessed and then they have to make a final request which might be a verbal request. The Coordinating doctor has to fill out a final review form, just like a checklist really, certifying that everything has been done appropriately. And then, the patient has to nominate a contact person who fills out another form and that is the person who will be responsible for returning any unused medication back to a dispensing pharmacy within 15 days of the patient dying. The doctor then basically submits a permit to the Department of Health and Human Services. Now, when they apply for a permit, they either apply for a self-administration permit, that is the patient is going to self-administer the medication or applying for a permit where the doctor will administer the medication. The presumption, and around the world, is most cases it's a self-administration, but if the patient is incapable of administering the medication themselves then they can ask for the doctor to do that. In Victoria, you have to apply for a permit for one or the other. The Pharmacist has to include a labelling statement and has to report to the board that the medication has been dispensed – the statement up there is part of the statement that is under the regulations. And then what happens with the medication, the medication has to be kept by the patient in a locked box and this is not something I have just made up, it is in the regulations. For those of you who go, 'oh where did they find that from?' it is actually the same requirements for keeping a gun under the Firearms Act. The requirements for the permit are very similar, the way it has been designed – it is very similar to the process of applying for schedule 8 medication. And I think what the government have tried to do is make these things feel and look similar to doing other things – so this has been taken from the Firearms Act. So, you have your locked box up there. Now I know one of the hospitals in Victoria is talking about – because one of the requirements is patients have to safeguard this medication and so there is some discussion around at the moment – do you have to take the locked box with you if you have to go into hospital, and if you take it with you, is it going to fit into one of the drawers beside you bed? And will the nurses have to write it up as a medication? I don't know if Brian has got any views on that, but these are the sorts of questions that are starting to come out. So, instructions are given for self-administration by the Pharmacist and the doctor. If the doctor is administering the medication to the patient they have to have a witness with them, and there are requirements under the legislation of what what they have to do, they have to be satisfied that they patient is not coerced, they still have capacity, even though they may not be able to administer the medication themselves, they still have the capacity to make the decision. And, as I said before, the contact person has to return unused medications. The evidence in Oregon is interesting, it reveals that about 20% of people actually died before they completed this process – you are starting to get a feel of the length of this process, and in fact you can't go from the first request to the final request in less than 10 days, the legislation says not earlier than 10 days. And I think in Oregon about 20% of people had died before they had completed the whole process. I think from memory about 30% - what's interesting is of the people who went through this process and it's not huge numbers I'm sure Brian will explain that, not huge numbers, but of the people who have gone through the process and have got the medication about 40% actually don't go through and use the medication. When they surveyed people in Oregon in 2016, the reasons why people were going through the process, about 90% of them was autonomy, about 65% said dignity, which perhaps gives you an idea of people who are interested in accessing this process. For those lawyers in the room, the cause of death is actually the underlying incurable

illness or medical condition, it is not the Voluntary Assisted Dying, it is not a reportable death, but it is a notifiable death, that makes sense. You don't have to report it, as you would a reportable death, but you do have to provide information to Births Deaths and Marriages and the coroner, and then the Births Deaths and Marriages report to the Voluntary Assisted Dying Review Board, so that is how they keep an oversight. As I said before, the legislation specifically states that there is no duty to provide assistance, you have no duty to assist an inpatient who comes and asks for assistance and there is no requirement for you to refer on to other doctors if you don't want to assist. There is protection from civil and criminal liability under the legislation for doctors and obviously from our point of view and having been involved in this type of legislation before this is one of the biggest concerns from a Medico-Legal perspective, is ensuring there are proper safe guards in place for doctors. There are 9 offences I think I counted up under the legislation. This legislation goes to 130 pages, 143 provisions I think, it is a long document. And I think I counted about 9 offences. One of the offences is not to submit the forms to the board on time. So, for our doctors who might get involved, you are going to have to have a good checklist to make sure they do submit their forms on time. The offences are things like coercing someone or trying to induce someone to self-administer medication. There is an offence for doctors who have a practitioner administration permit, that is they agreed to assist the patient, it is an offence to not do that within the bounds of the legislation. So, it is going to be really important for those doctors that they do follow the process outlined in the legislation. So that is a bit of a summary there, I won't go through it all. I counted up 9 forms or permits under the legislation, everyone has to fill in a form, the Pharmacist has to fill in a form, the contact person has to fill in a form, Coordinating Doctor has to fill in a couple of forms. So again, if you were concerned at all I think this allays your fears around is there a rigorous process? I think the answer is yes, there definitely is a very rigorous process. Just briefly in the last few minutes, before I hand it over to Brian, so that is what the Victorian's are looking towards in June next year. What I have just got to quickly reflect on is what we're seeing at Avant (and I've been speaking to Julian MDA National as well), these queries that are coming. Perhaps we see, and we have seen a peak in these queries in the last few months: it does anecdotally seem to be attached if there is a lot of media attention, like Professor Goodall's death, a well-publicised death – it is not clear if there is a cause and effect there, but we definitely see little peaks in queries. And I just thought I'd share with you some of the queries we are receiving and some of the concerns doctors are expressing to us about their medico-legal position and their ethical position when faced with these queries from their patients. And I guess the starting point from an ethical point of view is that the AMA position statements fairly clear that doctors shouldn't be involved in interventions that have as their primary intention the ending of a person's life. But the AMA has also recognised that doctors have different views on this and I think have stated that it really is a matter for society and government to make a decision ultimately on the legislation in this area. Obviously the medical board view, as well, is that if you are undertaking an act, this is obviously outside of the law and legislation, then you are risking a professional misconduct, prosecution as well. So that is your ethical position. And the law in NSW, it is not a crime to commit suicide. It used to be, it was removed, and it is no longer a crime to commit suicide, which is important for doctors to remember. It is however, a crime to aid or abet suicide. And this is the issue of greatest concern to doctors who are asked about assisted dying from their patients. Anyone who incites or counsels another person to commit suicide – some of you may have read about a man, in QLD last week I think it was, who counselled his wife who had suffered from depression to commit suicide because he was after her \$1.4 million life insurance money. He got 10 years for counselling her to commit suicide and got another 6 years for assisting her in her suicide. So, they are offences that the courts do take seriously. And so, these are some of the queries that we have received, down to the bottom there, the "travel to Switzerland to end my life". I don't know from reading the media reports whether Professor Goodall got a medical report from one of

his doctors, but the centres in Switzerland like Dignitas, Eternal Spirit I think and some other one, usually require a patient to provide a medical report outlining their medical condition and their stage of life. The question that has come up for us, and I know other NGO's as well, is providing a medical report to a patient in those circumstances potentially aiding and abetting a suicide? Even though a doctor might think they are doing the right thing, are they potentially putting themselves at risk by providing that report? The British Medical Association in some guidelines that were updated in 2015, took the view that that was a real risk and advised their members to decline to provide medical reports because of the risk that they could be seen to be aiding and abetting suicide. That is a view we have essentially taken as well; the risk is probably low. But this is still a very grey area, and as you can see the penalties are significant and so the answer really is in those situations to offer the patient their medical records which they have a right to receive. We are also receiving calls and queries from patients and maybe this is a reflection of the demographic, the age – dare I say the aging baby boomers – the people who are coming into their doctors and saying “I have decided to end my life, on the 15<sup>th</sup> of March” for example. They don't have terminal illnesses, they generally may be elderly and physically frail but mentally alert but deciding that they may want to take control of the end stage of their life. So, we are really having a shift away from an unethical medical-legal perspective, away from assisted dying and terminal illnesses and perhaps what we are seeing is another phenomenon that will need to be dealt with from medico-legal organisations. Obviously the question we have is do you need to report that to the police, and as I said suicide is not a crime, so if you are reporting to the police what are you actually reporting? I am not going to resolve all these issues for you tonight, I just thought they would raise them with you as examples of what we are seeing in this area. Similarly, dilemmas around not replacing batteries to a pacemaker or the other ethical dilemma turning off the batteries to a pacemaker and what impact does that have? Is that an active intervention that would be in contravention of the ethical standards and potentially aiding and abetting in suicide, if that was the intention for why you were doing it. And one more I've had recently “how much insulin do I need to end my life?” Can a doctor tell a patient that when it is in the context of someone whose thinking about planning not today, not tomorrow but down the future?

So I am going to hand over to Dr Owler just to give you a bit of an overview of the consultation processes, as I said, of the legislation we have just gone through.

**Dr David Gronow:** Thank you. We will have questions after both speakers. So, it is my pleasure now to introduce Professor Owler. He is well known I think to all of us, but he is a Sydney based Neurosurgeon, past President of the Federal AMA and the NSW AMA, he was chair of the Victorian Committee on Voluntary Assisted Dying, which we have heard about and he is also the past Director of Go Gentle Australia. So welcome, Brian.

**Professor Brian Owler:** Thank you. If you asked me a couple of years ago if I would be standing here giving a talk about voluntary assisted dying I probably would have laughed at you, but it has been quite the journey over the last few years. And it really started with the death of my father, as it has for so many people, personal experience has really shaped many people's opinions, particularly advocates in this area... I was actually President of AMA NSW at the time, and he died a terrible death. Now ironically he would not have been able to access the Victorian legislation, even if we were in Victoria. But to me, that put in my mind that there had to be a place for this type of legislation, something that had to be considered at some point along the way. And so it is my personal experiences, as well as my professional experiences, that really shaped my attitudes to it. While I was President of the AMA I spoke quite little about this subject, it wasn't a subject that was really hotly debated at the time, thankfully. I mean, Andrew Denton wanted me to go on his podcast

and be interviewed, and I resisted that because I can do a 30 second interview and run the AMA line that doctors shouldn't have any role in causing the death of a patient, that it is a matter for society and the government. But having gotten to know Andrew Denton over the years I know that putting up with an hour or longer of Andrew Denton probing in an interview, it is not going to come out well on his podcast, so I resisted that. But after I finished my term as AMA President, it was something that I started to look at and this got back to Jill Hennessy, the Minister for Health in Victoria and Jill was a very passionate advocate on this issue, as she has been on a number of issues, but she was really the one who was driving this in Victoria. Now as it happened there was an upper house parliamentary committee that had been established, on end of life choices, part of their legal and social issues committee, and it was chaired by Ed O'Donohue, the Liberal party MLC. That committee had been working over a number of years and they'd heard very strong testimonies, particularly from the coroner, about the horrific ways that people in Victoria had been taking their own lives and many of them had a terminal illness. That committee travelled to a number of jurisdictions, including Oregon and Europe, and saw first hand how the legislation worked in those countries. It was a very thorough report which focused not only on this issue but also on palliative care and advance care directives and planning, and so it is quite a long report, but the final recommendation of that committee was that the Victorian government should look at legislating a framework for voluntary assisted dying and proposed a very broad, very thinly detailed framework about how they might do that. As I said, Jill became aware that I might be interested in this and asked me to chair a ministerial advisory panel on voluntary assisted dying and that panel came together at the start of last year. The arguments for had been well established, the main argument for was really that not all pain and suffering can be relieved through palliative care. And it is not that we are against palliative care, people that advocates for voluntary assisted dying are not anti-palliative care, it is often painted as us vs them. I am a strong supporter of palliative care, as are all members of the committee and all of the people I know who have worked on this topic. It is just that palliative care cannot solve the suffering of all patients, and palliative care themselves say that. The profession themselves, when the AMA surveyed on this issue, know that many people still die without having quick relief of their suffering, they are beyond the normal reach of our medical techniques. There are many arguments against, of course. Many of the arguments, frankly, are part based on a religious moral view, and I have no problem with that. I have no problem with people objecting to voluntary assisted dying, my objection is when their morals are placed on other people who have a different view and obstruct them from having their suffering relieved, I think that is the issue that I have with some of those arguments. But I absolutely respect people's religious views. The arguments about slippery slope in terms of the numbers, the scope and the legislation being constantly expanded, do not hold up when you look at this objectively. Oregon, for example, now has been in place for 21 years and has never had any change to its legislation, Netherlands has been in place for 16 years and has not changed, Belgium has been in place for 16 years and has had one change in 2012. So the argument about it constantly expanding once the legislation has been established does not hold up. The numbers have increased, up until recently actually, but then of course started to level off and I can show you some data about that later. Many of the arguments come from concern for the vulnerable and certainly that was the biggest issue that I had, was people being coerced, about elder abuse, about the vulnerable in the community being subject to abuse. Now the Supreme Court of Canada looked at this when they went through the process in Canada and they called experts from all over the world, including all the jurisdictions where this legislation is in operation, and they could not find any supporting evidence, objective evidence that abuse was occurring where this legislation was in operation. So the committee was made up of those people there; Margaret O'Connor is an academic, professor in palliative care nursing; Ian Maddocks, known as the grandfather I guess of palliative care in this country, he was really the first palliative care specialist in this country; Roger

Hunt is from South Australia, he is a well known palliative care physician there; Mary Draper was the consumer representative who is extremely valuable; Tricia Malowney, well known in Victoria as a disability advocate; and I put the lawyer down the bottom, Julian was a public advocate in Victoria and is very well known, I'm sure many people in this room know him. That panel, I have got to say, thrashed out every single detail of this legislation, often for hours and hours of argument, and people's thinking in the room would change - it is remarkable to see the way that lawyers and doctors think when we get together - how the different perspectives come together. But I think the way that committee worked - and Julian has gone on to be responsible for the implementation process, subsequent to the legislation passing. So our role is really to go through a consultation process, so we have 14 round tables and these would run for several hours, we would have about 50 people in the room, I went along to the first one and I have got to say I thought "I'm not sure how this is going to go, you know we've got people who support it, obviously people that are against it in the room." Every single consultation session, it was constructive, people engaged, made thoughtful suggestions, even though they might have been opposed to voluntary assisted dying they all wanted to make sure the law that went up to parliament was the best law that we could have in Victoria. We also had a number of stakeholder consultations, we had a discussion document which invited written submissions, which we got many, and it wasn't ever about "do you support voluntary assisted dying or not?" it was about how we address the details of the law. And we divided it up into the eligibility criteria, the request and assessment process, and then the overview or oversight process. Now the first thing we did, because I think to make these decisions we had to have some guiding principles about how we looked at the legislation. Every life has equal value, we looked at autonomy, to many people this issue is about personal autonomy, they have made decisions their whole life about them and their family, they have been responsible for running companies or running their day to day affairs, but suddenly when they are sick and have got a terminal illness, they can't make a decision for themselves. I think in a way we look at people who are ill, particularly who are elderly and ill, we often get questions about that. It had to be an informed decision and it was about minimizing suffering, that is what this is about at the end of the day. I wanted to make sure that we supported the therapeutic relationships that existed, so when people had a good relationship with their own doctor hopefully we would support that relationship. But we also had to be open to the idea that people's individual doctors might not want to participate in this process as well. Just talking about this issue opens up a whole range of discussion around death, about dying and people's preferences. Of course, the rights of the individual had to be balanced with the safeguards for the community and particularly for vulnerable people, and all people had to be shown respect for their culture and beliefs in this process. So, when you go through the eligibility criteria and compared to the eligibility criteria that was put up, it did change. There was no timeframe initially in the framework that was put forward, but we felt that we needed guidance, not only for the patient, but also for the doctors that are assessing the eligibility criteria. What we put up to parliament was that there should be a 12-month window, now that was changed, as parliament upper house amendments, back to 6 months, but we kept in the 12 months. The rationale for that was, 12 months was chosen particularly for conditions like neurogenetic conditions where the trajectory of their illness is often longer than a patient with cancer. And probably the one criticism of the Oregon legislation, where at 6 months people with MS or Motor-Neuron Disease found that difficult to access, the level of suffering and the length of suffering they had to go through to get access to the legislation would be increased. Now suffering, at the end of the day, is subjective. So, having qualifiers about suffering that it had to be intolerable suffering, or it had to be severe suffering, but at the end of the day only the patient can assess that, it is not something that a doctor can say "yes your suffering passes the test," so it has to be suffering that cannot be relieved in a manner that is tolerable to the patient. So, it is up to the patient as to what treatments they decide



to have. This is a law about people who are dying, it is always important to remember that, it is for people who are dying and are suffering. We had to recognise those non-cancer illnesses. Decision making capacity is probably the most important part of this, and decision-making capacity is for decisions specific and has to be in relation to voluntary assisted dying and it is assessed at multiple points along the way. Now people with mental illness or disabilities, mental illness does not qualify you for voluntary assisted dying. If you have a mental illness, you are not excluded from being able to access voluntary assisted dying, provided that you have decision-making capacity. And the same when it comes to disability as well. The assessment process is a very formal process, as Kate outlined before, it has to be requested by the patient themselves. It is a very strict thing that we cannot initiate it as a doctor. You can ask about voluntary assisted dying without actually triggering this process, you can always go and seek information from a doctor should you want to. And this is all based on a normal therapeutic relationship, that you can request a second opinion. And you need all the interpreter processes there as well, and they have to be qualified interpreters. If you stop the process, you have to go back to the beginning, so you have to be very committed to undergo this. And I guess that is one of the things that we really struggled with, is the very difficult process for someone who is dying and is suffering to actually go through. But at the end of the day we wanted a conservative piece of legislation. It shouldn't be easy, it has to be a robust process and that is what we have ended up with. There are many advocates who criticise this process because it is so stringent. The doctor process is really that of a coordinating doctor who has the essential role of the one who takes the request at the beginning and then has responsibility for coordinating along the way. Really, the second opinion or the independent opinion is the consulting medical practitioner. Now it is really important that both of those medical practitioners undertake assessments independently, that the person meets the eligibility criteria, that they understand the information that is provided to them, they have to provide information about the nature of their condition, the treatment options available to them, about the palliative care options as well, and the likely effects of those. They both have to be convinced independently that the person is acting free of coercion and voluntarily, and of course that they have decision-making capacity and that this is an enduring request. If there is any doubt along the way about decision making capacity, they must refer to someone who can assess that, not necessarily a psychiatrist. Of course one of the arguments is that mandatory referral to a psychiatrist, but the psychiatrists themselves did not want that, they don't want to be seen as the gatekeepers. Now if someone has a history of mental illness and they want to make sure "yes this person has decision-making capacity," there should be a role. But it might be a geriatrician, in an older patient who might have decline in cognitive function. So any medical practitioner can conscientiously object, they don't have to participate. But just like anything else, you can't impede someone's access to a lawful treatment. So, if someone wants this, you can't obstruct them. But there is no responsibility to refer them on - as there is in Victoria's abortion legislation- and obviously there are time constraints around that. That's why there is the responsibility of referring when it comes to abortion. As Kate outlined before, you do have to have senior medical practitioners. We want to make sure these are people with relative experience and seniority for undertaking such an important process. There is a lot of monitoring of the medication: people didn't want the medication out in the community, so you need to monitor when it is dispensed, nominate a contact person so we can follow up afterwards what happened to the medication. 30-40% of people in Oregon die without taking the medication, because just having access to it when they want it is just comfort enough, it gives them that sense of control. The locked box – don't talk to me about the locked box – all this legislation was led by the ministerial advisory panel except I do not take responsibility for the locked box. There is a lot of mandatory reporting along the way about the requests, the results of the assessments, and of course when someone completes that process and about dispensing of the medication as well. So essentially, yes, this is a

self-administration process, the self-administration is the final autonomous decision, taking that medication. We also want to make sure, particularly people who might have motor-neuron disease that can't physically administer the medication, or they might have a stomach cancer where they can't digest the medication, also had access to the legislation. And we didn't want people taking the medication because they were worried they were going to lose that physical capacity. So, that is why there is the extra option of having a medical practitioner perform the administration in those cases when the patient cannot do it themselves. If you like, it is a safeguard, not prompting people to take it too quickly, which I have heard patients talk about in the past. Lots of reporting along the way with prescribed forms as well. And we did want to try and respect people's privacy, there was a lot of discussion in a debate both in the lower and upper house about whether it should be on the death certificate or notification of death, thankfully not a lot of people understand the difference between a death certificate and notification of death. It most closely resembles the Oregon example, but it is quite unique legislation. The rate in Oregon is about 0.39% of deaths. So in Oregon, 6 months, you have to have a terminal illness, the legislation is a lot less prescriptive. They had, in 2016, 103 deaths and about 200 prescriptions that were given, so the number of deaths is much lower. So, you expect if you took that figure to Victoria, that is sort of 150-200 per year. And that is after a period of time. The opponents often talk about the rise in the uptake, but it is like anything, people don't use it much at the start, as people start to become more familiar with it and more comfortable with it, people will start to use it. And actually in the last few years we have seen that usage actually start to plateau. So, it took a long time, as I said it's 21 years now that legislation has been in operation for and there are very good statistics. When you look at the Netherlands and Belgium, the numbers are much greater, they have a much more open and liberal law, they always have. It's not that the scope has expanded, the scope has always been there under their legislation. So, they have a much more liberal law, it comes from where this originated from in the first place, particularly in Belgium the palliative care community put this together, in the Netherlands it actually came through their medical association, the Royal Dutch Medical Association. But if we look at the percentage of deaths, it is starting to plateau. Again people, this is specifically for medical practitioners, they are not required to participate, they can't initiate a discussion. There are protections for health practitioners and for paramedics, in terms of if they are called to someone or the medication doesn't seem to be working, do they have to resuscitate them? Protections around that, and as long as people follow the law and act with best intentions, they are protected. So the implementation process, included in the legislation is an 18-month implementation process, to make sure that we get people trained, get people ready, also to allow people and organisations to respond. So people have to organise how they are going to deal with it, particularly in some organisations. So, that comes around on the 19<sup>th</sup> June 2019 and they are well advanced in their implementation. The medication is something that people have been talking about a lot, it is not prescribed in the legislation, clinical practice is not prescribed in the legislation in anything else. If you want good medication, you go with the best medication that is going to have the best effect. So it is compassionate, and it is safe; compassion, choice and control. That is the guiding principles to the legislation and that's what I believe that this is about. It is about the alleviation of suffering for people who are dying. It provides a choice, it is not a choice about living and dying, as I said these people are dying, it is about the timing and manner of their death and it respects their autonomy and decision-making, and I do think it has very strong safeguards for the rest of the community and health practitioners as well. In terms of what is happening in the rest of the country; Western Australia has gone through this process, they've had an upper house review, they've released a report and a very broad framework that they have put forward, they have announced their ministerial advisory panel and they will introduce legislation next year. South Australia, of course, has gone through this process recently, I'm not sure when that is going to come back up there; Tasmania are recent as well. NSW I think is a very long way, it

depends what our parliament is going to look like after next March. QLD, now that they have done an abortion reform, the next thing is going to be voluntary assisted dying, so I think you will see that come up in QLD. With the Territories, I was with Marshall Perron earlier on in the year working with the senate on the legislation that he put forward about repealing the Andrews legislation and restoring the right to the Territories to legislate. I was working with Marshall Perron out of David Leyonhjelm's office, which is a sentence I never thought I would say. But that was a very closely run thing, and I think there were only two votes in it in the end. I think that issue will come up again, particularly in the next parliament and I know a number of people who have got legislation ready to go there. Thanks.

**Dr David Gronow:** Well thank you, I'm sure now there will be some questions, so we are willing to take some questions from the floor.

## **Q&A**

**Q: (Dr Julian Walter)** Brian, I am just interested to see, have there been many more guidelines that have come out in the countries that do have voluntary assisted dying in terms of what medication to use and how much and how they are given?

**Professor Brian Owler:** Yeah, there are. The medications are varied, there are a number of medications that they use – Nembutal is one of the most commonly used, but there are a number of related medications. This law now exists in 7 states in the United States, the legislation is very similar in those states. Some have gone to using a variety of medication because, we use the word “cocktail” sometimes to describe using a lot of medications – I mentioned that to someone in the media once and on the front page was “Cocktail washed down with OJ” as the headline. But there are various medications and it is a process as well, you have usually got to pre-medicate someone in terms of an anti-emetic before they take it, otherwise people vomit the medication. When you look at the medication and its effectiveness, there have been a number of cases where people have taken the medication and it hasn't worked. In some cases the medication has been too old and lost its effect, and in some cases people don't take it in the right way. So you do have to have that education about medication as well. The medication is not prescribed in the legislation, there will be guidelines in Victoria and they are working with one of the university pharmacology departments on that particular topic and as I understand it they have made good progress with the TGA as well.

**Q:** I just have a question in relation to the threshold issue of having to verbalise your desire to access the legislation, what happens if a patient isn't able or has become through their illness unable to verbalise their desire?

**Professor Brian Owler:** Good question. That is also included in the legislation, so it is not that they just have to make a verbal request, instead of oral request they can use other forms of communication, and in some of those forms of communication they have to have a particular interpreter. People still need to be able to do that themselves and make a clear request, but it allows for other forms of communication.

**Ms Kate Gillman:** In the legislation it refers to the word “gestures,” you can either verbally do it or through gestures. And I think the regulations have just come out recently and prescribed interpreter services as well.

**Q:** The policy that restricts a doctor from raising the discussion themselves, how would that be proven?

**Professor Brian Owler:** I think you have got to remember, this is a process that most people will go through with a supportive family and in the context of an arrangement with their medical practitioner that they have probably known for a long time, the construct often gets drawn up that a person goes in and next thing you know someone is pushing the voluntary assisted dying and they go through this process. The process is designed so that multiple people along the way all have to be satisfied that this person is acting voluntarily and free of pollution. So I think you would be very selling person to try and raise this, because there are strict penalties for people that do, and this process has a voluntary assisted dying review board that will oversee each step of the way and review all of that documentation and if someone acts outside of the legislation they will be prosecuted.

**Q:** My question is though, what's to stop a patient from saying "my doctor brought this up" when they didn't and in reverse, how would a patient prove the doctor did bring it up?

**Professor Brian Owler:** I think the main point is to make sure the relationship is protected under the legislation and they aren't coerced or taken advantage of – but if you are arguing how in a private conversation who said what, well that is a difficult thing to prove, but as I said the main point is to make sure we protect people from people who are acting unethically or actually trying to coerce people.

**Q:** What is the atmosphere for changing the Crimes Act and for example the AMA's stance that make it a potential crime or professional misconduct to participate in this, for a doctor?

**Professor Brian Owler:** I don't think that the AMA says professional misconduct –

**Q:** Is there a risk that you would be found guilty, by the medical board?

**Professor Brian Owler:** Oh sorry, the medical board. This is a lawful treatment in Victoria, so the doctor is protected. They can't be prosecuted by the medical board.

**Ms Kate Gillman:** The legislation specifically says that it is not professional misconduct and it is not a crime.

**Q:** I notice that you said you have to be a resident in Victoria for 12 months before you could make use of this, what triggered the 12 months? And what can other states do to shorten that or change that?

**Professor Brian Owler:** The original proposal said "ordinarily resident of Victoria" which is the sort of wording that is used in just about every other piece of legislation in Victoria and I think right around the country, but when this was debated, particularly through the upper house where the numbers were very tight, people put in for a number of amendments, they wanted to make sure that there was very criteria about people not coming from interstate, so that is how the 12-month came about. People were concerned that people would come across the border and cheat the system somehow.

**Ms Kate Gillman:** I think in the Northern Territory some of people who died in the territory were not from the Territory, so I think from some really good consultation one of the things that was taken into account is really to stop the medical tourism.

**Q: (Andrew Blandford)** I have two questions, firstly given the technical nature of the steps that have to be gone through, if there is any failing in the technical requirements, does that invalidate the whole process and undermine the protections of the people who are involved? And the second question being that, given that there are such strong limitations on the process, is there a sense that

it might not actually show compassion to a lot of the people who aren't included, from accessing assisted dying under that legislation?

**Ms Kate Gillman:** There is a provision that specifically says it is not invalidated through not filling out the form in exactly the right way, there is some leeway there in terms of form substance, but in terms of the second question –

**Professor Brian Owler:** And the secretary of the department has to approve the permit and they have to check that they have been done satisfactorily. There is this balance between constructing legislation that has all of those safeguards in it and then providing a piece of legislation that someone who is suffering and dying can access, and I think it probably is on the stricter side but I think there was also a political reality of passing this legislation and it was a very closely riding debate, the numbers were really tight and I wasn't sure right up until it went through that this was actually going to go through either house. So there's a reality there, and I think it is much better to get it into a medical framework than having the other suggestion which was administrative tribunal type arrangement where people would go along and have to plead to a tribunal about whether they should access voluntary assistive dying, so I think this is a much better way.

**Q: (Andrew Blandford)** I wasn't feeding you criticism of the process or the legislation, but maybe putting in another way, is there any sense of the proportion of people who might otherwise want to access this process but would be ineligible under the legislation?

**Professor Brian Owler:** That is hard to put a figure on. I think what is clear is that a lot of the people who think the legislation doesn't go far enough, I had one lady in my office and we were going through this process just talking to her about the back pain when she knelt in church and then she said "now about this voluntary assisted dying, my criticism, is it doesn't go far enough," and for a lot of people, the fact that it doesn't include things like dementia, they are upset about it. And that is something that is going to be debating in WA. I don't support that, because I think that people have to have decision-making all the way along. It brings up all sorts of practical issues around when do you actually go ahead with voluntary assisted dying? So you can't request this, for instance, in an advance care directive, it has got to be something that you make decisions with all the way along.

**Ms Kate Gillman:** In Belgium, I think it is, you can put it in your advance care directive and if you are suffering from dementia you can anticipate it. What's interesting, in the Netherlands the second consulting medical practitioners really becomes a subspecialty. I think there are a group of specialists there now that assess 80% of the cases, but of those they reject 25% of them. But remember there are no terminal illness requirements, it is more on suffering ...

**Q:** You know that there is an Act centred around death, dying, pain, suffering and incurable diseases; could there be scope, maybe further down the line, that if a parent or a guardian had a child or a person they were legally responsible for that was in pain, suffering etc, would they be able to access the legislation? And I know that the provision is that they are over 18 years old.

**Professor Brian Owler:** No –

**Q:** - Is there any that exist?

**Professor Brian Owler:** So, the change that was made in Belgium was for that purpose and I think there are 4 cases in Belgium where that has happened, and there is a lot of stricter criteria around that. This is one of the slippery slope arguments, that it is going to constantly expand, but we can't predict what the parliament might do in 5, 10, 20 years, that is up to society at that stage. Any parliament can repeal the legislation and they can change it the way that they see fit. So, can it

change in the future? Yes. But I tell you, this debate has been going on in this country since the Rights of the Terminally Ill Act in the Northern Territory in 1996, and it has taken more than 20 years to pass another piece of legislation, despite about 50 attempts in various parliaments around the country. So if it has taken this much to get this piece of legislation through, I doubt very much that anyone will be changing the legislation any time soon.

**Q:** Is there any idea at the moment what the training for the doctors will involve?

**Professor Brian Owler:** Yes, they are in that process now and I know that early next year they will actually be rolling out that training. So, the training is obviously about the responsibilities under the legislation, first of all, but then it is also about issues to do with making sure people are well trained in identifying issues of elder abuse or coercion, looking for signs of coercion and making sure people are making that voluntary request. Then of course there will be education around the practicalities and the guidelines about how to do it, and then support as well for the medical practitioners who might have a role in this, some people may find it very confronting, some people might not want to do it but others who will find it confronting, and those people need to get supported as well.

**Q:** On the review board, what is the mix of expertise or places people come from and what is the tenure of members on the board?

**Professor Brian Owler:** It is appointed by the Minister, the board has I think been established and you might know the people better than I?

**Ms Kate Gillman:** I haven't heard who they are yet.

**Professor Brian Owler:** I think it is one of the Victorian Supreme Court Judges who is chair of the board. We didn't prescribe – originally there was a prescription that it has to be a doctor, it has to be a nurse, like any board the Minister should appoint appropriate people with an appropriate mix of skills to make sure that the board functions.

**Q:** Isn't there a four-year tenure for each member?

**Professor Brian Owler:** I couldn't tell you that off the top of my head.

**Q:** Would there be a register of doctors who are trained and how would a patient know how to access and how to find a person?

**Professor Brian Owler:** Not really, no. So that is one of the challenges because obviously there will be a number of people going through the training but also that notion of having a register of people that might then be targeted by opponents is also a bit concerning. I know they are looking at ways of trying to help facilitate patients in terms of their access in those circumstances, but there won't be a website listing doctors that have been trained in the scope of that.

**Dr David Gronow:** I am going to take the last question, what if the request goes to an allied health provider? What protection do they have, what role do they have in this legislation?

**Professor Brian Owler:** They can't do it, it has to be a medical practitioner.

**Dr David Gronow:** But are they protected in terms of – do they refer, do they discuss it?

**Professor Brian Owler:** Well they can discuss it, people can request information and they have every right to do so. There is nothing stopping someone from going and having a conversation with any doctor or allied health professional, but they can't participate in the process and there is no obligation on that practitioner to then make a referral, they just can't impede that person's access.

**Dr David Gronow:** But they can't promote it either?

**Professor Brian Owler:** No, I mean they can suggest that they go and talk to a medical practitioner, that is the responsible thing to do and it is basically guided by the ethical guidelines that any registered health practitioner has to act under. I think that is the other aspect of this is there are lots of existing laws and guidelines that people have to abide by, this legislation doesn't exist in isolation and they still have to abide by all those other obligations as well.

**Dr David Gronow:** I need to draw this to a close. I would like to thank Kate and Brian for a really excellent talk and I think it has been very informative, and I would like you to join me in thanking them both.