



LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

(Reference: [Inquiry into end of life choices in the ACT](#))

Members:

MS B CODY (Chair)
MRS V DUNNE (Deputy Chair)
MS T CHEYNE
MRS E KIKKERT
MS C LE COUTEUR

PROOF TRANSCRIPT OF EVIDENCE

CANBERRA

THURSDAY, 26 JULY 2018

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Secretary to the committee:
Mr A Snedden (Ph: 620 50199)

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

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Privilege statement

The Assembly has authorised the recording, broadcasting and re-broadcasting of these proceedings.

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Witnesses must tell the truth: giving false or misleading evidence will be treated as a serious matter, and may be considered a contempt of the Assembly.

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Amended 20 May 2013

The committee met at 9.36 am.

**WILLMOTT, PROFESSOR LINDY
WHITE, PROFESSOR BEN**

THE CHAIR: I declare open this eighth public hearing of the Select Committee on End of Life Choices in the ACT in its inquiry into the matters referred to the select committee by the Legislative Assembly on 30 November 2017.

The hearing program for today and the committee's terms of reference are available online. The proceedings are public, are being recorded by Hansard for transcription purposes and are being webstreamed and broadcast live. I remind witnesses of the protections and obligations entailed by parliamentary privilege and draw your attention to the privilege statement. This is very important.

On behalf of the committee I acknowledge that we are meeting on the lands of the Ngunnawal people, the traditional custodians, and I pay my respects to their elders past, present and future and any of those who may be present today. We respect their continuing culture and the unique contribution they make to the life of this area.

Our first witnesses are Professor Lindy Willmott and Professor Ben White via phone. Can you confirm that you understand the privilege implications of the statement?

Prof Willmott: Yes, I do.

Prof White: Yes, I do.

THE CHAIR: Would you like to make a brief opening statement?

Prof Willmott: Yes, thank you, we would. Thank you for the invitation to appear before the committee today. My colleague Professor Ben White and I are members of the Australian Centre for Health Law Research which is part of the Faculty of Law at the Queensland University of Technology. I say at the outset that the views we express today are our own based on our own research in this area and we do not purport to represent the views of others in the centre, the law faculty, QUT or any other body with which either Ben or I are affiliated.

For the sake of transparency, before the committee asks us specific questions, we would like to state our position in relation to assisted dying. As a general proposition we believe the law should allow assisted dying in limited circumstances. We know that there are certain constitutional issues that make this problematic in the ACT, but for the moment we are leaving such issues to one side.

We believe a law of this kind would promote values that are important in a liberal democracy: life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable and reducing human suffering. We believe an appropriately drafted law that permits assisted dying would protect the vulnerable in our community.

We are happy to discuss our thoughts on what such a model would look like if that

would be helpful for the committee, but I note that we have outlined our preferred model in chapter 26 of the text *Tensions and Traumas in Health Law*, which has been forwarded to the committee already.

There is one final point we would like to make here: the committee has been provided with many submissions and will hear much evidence. There is no doubt broad and diverse expertise within the committee, but we wanted to take this opportunity to repeat a point we made in the material attached to our submission about weighing this evidence.

With our colleague Dr Andrew McGee, we wrote a piece for *The Conversation* about this point. I believe a copy of this article was submitted as an attachment to the committee. In it we invited Victorian politicians who were then considering their bill to distinguish between claims about morals, for example, all killing is wrong, and facts, which depend on evidence. People can legitimately have different views about morals. Some may not think all killing is wrong, and some may. However, if claims are made about facts, it is important to thoroughly interrogate the evidence provided to support those claims.

In relation to weighing evidence, a reliability pyramid has been proposed by a colleague, Professor Jocelyn Downie, which is also in your material. We invite you to question what evidence people are putting forward to back their claims about assisted dying laws. At one end of the spectrum are anecdotal claims—what people claim to have seen or done. This is of limited reliability. At the other end of the spectrum is a systematic review which puts together all the research done on a topic and critically evaluates it. Ideally that research is then further externally reviewed by another body, such as a court or, in this case, a committee.

This point is particularly important in the context of the claim often made that it is impossible for any legislative regime to be drafted in a way that protects vulnerable people. Assisted dying has been lawful in some international jurisdictions for a long time, and there is much research in to how the regimes are operating in practice. This research has been published in prestigious peer review journals and provides evidence that the vulnerable are not at risk as a result of legalising assisted dying.

Again, we are happy to talk to this point further during this session.

MS CHEYNE: You have written extensively about this and I want to draw out a little bit about what you have said about some of the arguments that came up during the Victorian debate, particularly about morals and testing the evidence. Are you able to expand on that a little bit for the purposes of evidence for the committee?

Prof Willmott: Yes we are.

Prof White: This goes to the conversation piece Lindy mentioned that we wrote with a colleague, Andrew McGee. This was in the midst of the debate that was occurring in Victoria and in the Victorian parliament about assisted dying. We were concerned about some of the claims that were being made and the way evidence was being used. We suggested a distinction be made between claims about morals: whether something should happen or not: whether something is right or wrong; and factual or empirical

claims: whether or not something is actually happening in practice. The reason for that distinction is that what justifies each claim is different.

Sitting underneath the moral claims, the moral views that are reached, are values. People will have, as Lindy mentioned in the opening statement, legitimately different views on values. We have suggested that where values are informing the moral position, they should be transparently stated. That is part of the opening statement where Lindy mentioned the values we rely on.

On the other hand there are factual claims. Whether those claims are true depends on evidence. As Lindy mentioned, there is a large body of peer-reviewed evidence which can help guide decision-makers, such as parliamentary committees, about how these regimes can and do operate in practice. In particular, in that reliability pyramid that Lindy mentioned, anecdotal evidence, we suggest, should not be given great weight at all. That evidence is a statement of one or two people about what they think or what they have seen. There is no way of independently verifying that and testing that, which is quite different from a systematic review which gathers together all the empirical research that has been done in peer-reviewed journals and tests and evaluates it.

That is the heart of the distinction that Lindy mentioned. Our suggestion is that people who make submissions to this committee should be clear about both of those things. Likewise, as parliamentarians consider this debate, they should also make clear what their values are and that that is why they reach a particular moral view. If they are suggesting, for example, that there are concerns about risks to the vulnerable or things like that, we suggest that the parliamentarians making those claims need to have that sort of robust evidence.

The last thing to add to that, which we mentioned in that *Conversation* piece, is that at times there may be a risk that people may have in-principle moral objections to assisted dying, but that is sometimes presented as concerns about practical issues, factual issues such as risks to the vulnerable. We suggest it is very important to be clear about the principle, the moral position. If there are separate concerns about evidentiary issues, they should be treated separately and explained separately.

MS CHEYNE: I note that you have also published an article about how Belgium allowed children to access an assisted dying scheme. That is something we have heard evidence about from others in this inquiry. Are you able to explain whether in your view that is a slippery slope or evidence of a slippery slope?

Prof White: There are different ways that people talk about a slippery slope. The type of slippery slope people are talking about there is that if we allow assisted dying to be available to a certain group, inevitably over time that would widen and other people who were not originally contemplated would be allowed access to assisted dying.

Thinking about the Belgian situation, it is probably an exception, so I should deal with it in general principle first. The Victorian law is largely modelled on the Oregon experience which was enacted 20 years ago and has not changed. Concerns that the law must inevitably change and must inevitably evolve over time have not really eventuated. The one exception—and, it is a very narrow exception—is in Belgium.

Their law in 2014 was expanded to allow very tightly circumscribed and limited access to what we would call Gillick-competent young people, for example, 16 or 17-year-old people who are capable of making an informed choice and meet the very rigorous test of being able to make their own decision. That is very limited and additional safeguards are added to this limited exception.

There is some more recent Belgian data out, but I do not think it has been translated into English yet. But when we last gave evidence on this subject, to the Western Australian parliamentary committee, from the time it was enacted in 2014 I think two or three young people had accessed that in that three or four-year period. When that law was passed there were lots of discussions about how the flood gates had opened, but that has not been the reality. It is very narrow and has been used very infrequently.

MS CHEYNE: And is it because someone's age is really quite an arbitrary distinction?

Prof White: That was the rationale for the change to the law in Belgium. The discussion there was that imposing a cut-off of 18, in their view—based on their inner political environment and their experience with assisted dying—was regarded as arbitrary.

I note that in Australia no-one is seriously contemplating access being allowed to minors. The legislative models that have been proposed across the country and that we have reviewed in another paper and sent through to you are focused on competent adults who are able to reach a view on this themselves.

MRS DUNNE: Prof White, could you elaborate a little on your decision-making pyramid you refer to in the submission. You say there are people who have moral views about the issue and that they cannot be in any way confused with factual concerns about the issues. In the context of this and looking at European legislation, you say the legislation has not changed, but the availability and the uptake has seen substantial increases through the time of the operation of legislation in other jurisdictions like those in Europe. What do you see is the reason for the increase in uptake and what are the factual issues in play that caused the increase in uptake of voluntary assisted dying, however described?

Prof White: You have raised a couple of issues there. The first one is the interplay between morals and factual evidence—empirical claims. We are not for a second suggesting that people cannot have moral views and different moral views. As we mentioned, our view is that it becomes important that the values which sit under those moral views be explicitly stated so people can clearly understand the basis for reaching a conclusion.

In relation to the empirical studies and factual matters, you asked for some clarification in relation to the reliability pyramid. We sourced that from a colleague in Canada, Professor Jocelyn Downie, who developed that in response to thinking about these issues herself. The question there is: is it reliable evidence which has been tested by peer review, published in top journals and so on and drawing a distinction between which sorts of evidence should be regarded as reliable and which should not.

The second point relates to the use of assisted dying laws. Here I point to a discussion in the Victorian ministerial panel report on assisted dying when thinking about how patterns of usage might change or evolve over time. Their view was that for all new health interventions—I think they used those words—initially there is a very limited uptake, in part due to lack of knowledge or awareness or people being comfortable and familiar with how that regime works. But, over time, as with other new things in the provision of care and services in the health system, that familiarity and awareness and understanding of its applicability can grow over time. I suspect that that was specifically foreshadowed in that ministerial report panel and is part of that changing pattern of use.

Prof Willmott: Although the claim that the uptake has increased over time is absolutely accurate, two important observations need to be made, that is, that there has been extensive empirical research, which we have already referred to, that the vulnerable have not been subject to euthanasia. So although there has been an increase in the number of people who have accessed the regime, the research shows it has declined for people being euthanased without explicit request. The data, the empirical research, indicates that the vulnerable are not at risk in those jurisdictions even though the uptake has increased.

The second point I make is that a fair bit of research has been coming out of Oregon in relation to looking at the cohorts of individuals who seek assistance to die under the Oregon legislation, and that data seems to suggest that it is the older, white, well-educated who are choosing to access assistance to die rather than vulnerable groups.

MRS DUNNE: But the Oregon model is somewhat different from the models in, say, the Low Countries, as a general description. There are at least media reports of cases of concern about lack of documentation and concerns about consent. Is that reflected in the research about the Low Countries?

Prof Willmott: Yes. There is also research about who is accessing assistance to die in Belgium and the Netherlands, and that research is consistent with the Oregon data. The second point I make in relation to the media reports is that I go back to that pyramid and invite the committee to really interrogate the facts which underpin those media reports.

We have all seen many media reports with assertions which, when investigated, turn out to be not correct. The claim I made earlier is that the research in the Netherlands and Belgium indicates that the incidence of euthanasia being performed without explicit request has declined over the years rather than increased.

Prof White: On that note—I am not sure if this was one of the papers provided to the committee—I have written with a colleague from Belgium and another colleague, Neera Bhatia, a paper examining some of those high profile cases reported in the media and reached some conclusions about the way they can or should be used in the Australian debate.

One of the key things which Lindy alluded to is that because we are talking about medical records and those sorts of things, by definition the media will not have all of

the information about a person's condition, illness, and wider things which are so important to how those assessments are made. I have reservations about the reliability and the usefulness of selected media reports that come out about particular cases. If that paper is not included in the materials, we can send that through for your consideration as well.

MS LE COUTEUR: I am interested in the situation of people who were competent and at that point stated they thought that in certain circumstances they would like to be involved with voluntary euthanasia and subsequently become less mentally competent but clearly have reached the physical conditions they were envisaging. We have talked with some people about the possibility of assisted decision-making. Do you have any views on what could happen to that cohort of people?

Prof Willmott: Generally speaking, in almost all jurisdictions a person would need to have decision-making capacity right up until the time that assistance is provided to die. We have analysed a number of the bills introduced in Australia over the past few decades and, invariably, the eligibility requirements are that the person needs to have capacity at all stages throughout the process. So at the beginning there needs to be a request made and that person needs to have capacity. That capacity needs to endure right up until the assistance to die occurs.

There are some models, for example the model in the Netherlands, where a person is entitled to make an advance directive or a written statement which includes a request to die and, therefore, technically they are able to receive assistance to die at a later point in time when they have lost decision-making capacity.

But I note that through discussions we have had with researchers in the Netherlands it is a little controversial there. Generally speaking, despite this provision in the legislation, doctors are reluctant to provide assistance to die where that decision-making capacity has been lost and the person is no longer at the relevant time able to confirm that they want assistance to die.

MS LE COUTEUR: Have you any information or views on determining the person's capacity at this point of time?

Prof White: Do I understand your question to pick up issues of supported decision-making and assisted decision-making?

MS LE COUTEUR: That is right, noting that physical decline is often accompanied by mental decline. We have had it raised by a number of people that they could see someone who has made clear what they wanted in a certain physical situation to then be in that situation but also having declined mentally and being deemed not to be competent to make the decision. My question is around decision-making and how you would work out capacity. I inform you of my personal point of view of having had a mother for a very long time in a nursing home where there were a lot of people who clearly could be in that situation.

Prof White: Based on the values we outlined in that book chapter which Lindy opened with, autonomy is obviously at the centre of our thinking on this. Indeed, all the models in Australia have really focused on that sort of approach—that is, if a

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person did not have capacity and was not able to competently and confidently request assistance to die then that should not be available to them, and they would fall outside those eligibility criteria.

MS LE COUTEUR: You do not have any views about how you determine competencies? Assisted decision-making is, as I understand it, something to help people who have a degree of competency. That is what I am interested in.

Prof Willmott: We do not have a particular submission in relation to the legal test around capacity. The test of capacity has been evolving and is very well-stated and understood in a whole lot of different contexts that relate to medical treatment.

Certainly, it is the case that in certain circumstances—for example for a patient in an intensive care unit—it can be difficult to discern what their capacity is. But the test for capacity we believe should remain the same, and a person would need to be able to in some way satisfy that test of capacity to be able to request assistance to die.

THE CHAIR: Thank you, Professor White and Professor Willmott, for giving up your time to speak to the committee. It has been very insightful. When available, a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections.

PERRON, MR MARSHALL

THE CHAIR: I welcome our next witness, Mr Marshall Perron, via phone. Mr Perron, can you confirm that you understand the privilege implications of the statement that has been sent to you?

Mr Perron: Yes, I do. I have read the statement and signed and returned the witness statement.

THE CHAIR: Thank you. Mr Perron, do you have a brief opening statement for the committee?

Mr Perron: I have a few words to say, yes. The elephant in the room before the committee and all of us who make submissions to such committees is, of course, reference number 5—that is, the effect of federal legislation on the ACT. All the committee's other references relate in a sense to reference 5 because without the authority to make your own decisions through the Legislative Assembly of the ACT, if the committee recommends proceeding down the path of voluntary assisted dying the parliament is unable to follow that recommendation.

For over ten years we have had before the federal parliament a series of bills to restore the powers to the ACT and the Northern Territory to address assisted dying if their parliaments so wish. A bill is before the Senate that will come up on 14 August this year. I presume committee members are aware of that. That is only a couple of weeks away. Unless that bill passes both houses of federal parliament on this occasion, I suspect it will be many, many years—possibly decades—before the federal parliament readdresses this issue.

It is a private members bill issue in the federal parliament, and that is the problem; only individuals are driving it and not parties. Unfortunately, private members bills in the federal parliament have a history of simply not coming up on the notice paper for debate, as we can tell by the fact that this matter has been before the federal parliament in the Senate for over ten years already.

There is certainly a lot of lobbying going on behind the scenes at the present time, but I am saying to the committee and anyone else in the room who are citizens of the ACT that anyone who feels strongly about restoring territory powers to address assisted dying has only weeks to badger their federal MPs.

Are members of the committee aware that the Northern Territory parliament back in 1997 delivered a remonstrance to the federal Senate and the House of Representatives beautifully articulating in parliamentary terms the case against the Euthanasia Laws Act? A remonstrance, as you are probably aware, is a very rare document prepared by a subordinate parliament to a superior. It is a statement of grievances. Unfortunately it fell on deaf ears in 1997. I can send the committee a copy of it if necessary.

THE CHAIR: That would be amazing, thank you.

Mr Perron: It is a beautifully articulated document and is as applicable today as it

was in 1997, as you will see if you care to read that. I am happy to respond to questions.

MRS KIKKERT: I have no questions, but I thank you for your time.

THE CHAIR: You mentioned territory rights in your opening statement so I will not dwell on that, although I sure we have a lot of questions around that. In your submission you specifically talk about issues relating to frank discussions regarding ending your own life when it gets to that point and that there are no laws to allow people to have those open and frank discussions. Can you expand on that?

Mr Perron: Yes, the point I am making is that a doctor can certainly talk to you about suicide with a view to talking you out of it or referring you to other counsellors or other sources of information or services that might stop you or at least talk you out of taking your own life. But a doctor cannot hold a conversation with a patient in a positive sense about their decision to take their own life.

Where a patient might want to seek advice, for example, if they had planned to take their own life in a particular way or they had assembled some drugs and they wanted to know if they take these drugs, will it end their life and not half do the job, a doctor cannot respond in a positive way to a person who is determined to follow that course.

That will change when voluntary assisted dying legislation is passed, as has happened in Victoria. Doctors will be able to engage in an honest and completely frank discussion for the first time with patients who are so determined. In many cases, I believe those conversations will well lead to a deferral or a putting off altogether of plans for suicide. Just the fact that a person can talk to a professional and not be fobbed off as, "Tut-tut, you really don't want to do this. You just need help, will certainly assist.

THE CHAIR: From a territory rights perspective, you obviously had a lot to do with a lot of the parliamentary decisions made in the Northern Territory. Can you expand as briefly as possible on some of the processes the parliament undertook?

Mr Perron: In what respect?

THE CHAIR: In the lead-up to the introduction of the legislation in the Northern Territory parliament.

Mr Perron: I am just casting my mind back; there was a procedure. I referred the matter to a women's advisory council that we had as standing in advice to the Chief Minister in those days. The Chief Minister could refer any matters to that council to examine and tour around the territory and take evidence on. It was not a parliamentary committee; it was an administrative committee.

I referred to them the matter of whether Territorians were satisfactorily accommodated in their dying stages. They came back to me after a while and said, "This issue is too hard for us. We don't have the expertise for it." I then wrote to all the doctors I could find in the Northern Territory to seek their responses. Subsequent to that I decided personally to introduce a private members bill on the subject, having

done some personal research into the arguments against voluntary euthanasia.

In those days, of course, there was no legislation anywhere in the world to refer to. There were papers written on the subject but there was no legislation. So I just took it upon myself to do it as a private members bill so that my colleagues in parliament from all sides had the complete option to oppose completely what I was doing if they so chose.

THE CHAIR: I note that although we are a select committee, we are all women.

Mr Perron: Well, I hope you do not have to come back and say, “This issue is too hard for us so someone else should handle it.”

THE CHAIR: I am sure we will come up with some wonderful recommendations.

MRS DUNNE: You spoke about the remonstrance that the Northern Territory parliament issued back in 1997. The ACT parliament has on one occasion issued a remonstrance—not on this matter but another matter—where legislation was overridden by the commonwealth parliament. You said that the remonstrance was a mechanism of issuing complaints from a subservient parliament to a superior parliament, so you recognise that the constitutional status of the territories is different from the states?

Mr Perron: Absolutely. Section 122 of the constitution certainly gives the commonwealth parliament the power to make laws for the territories. That is standing and unquestioned in my view. The federal parliament certainly had the power to do what it did. The Euthanasia Laws Act is a valid act of federal parliament; it is just morally wrong in my opinion and democratically wrong for obvious reasons. The 660,000 Australians who have decided to live in the territories should not be discriminated against compared to the 24 million who do not live in the territories. It is as simple as that to me.

MS CHEYNE: I want to talk also about the federal legislation. For those of us who were not around or necessarily paying attention—I was in school in 1997—I want to get a sense of when you realised that the Andrews bill was going ahead, how you were made aware that that was happening whether federal parliamentarians had started agitating with you about what had been done in the Northern Territory.

Mr Perron: I am not sure when I became aware of it, but there was no secret about Kevin Andrews’s intention. He was urged, I understand, by then Prime Minister John Howard to take an interest in what was happening in the territory, and there were concerns, obviously, from John Howard and Kevin Andrews about it.

Kevin Andrews at one stage came to Darwin; I remember meeting him. We had a discussion about it. I do not remember a lot of the details. It would have been a respectful discussion, I am sure. But he was driven by the fact that the territory had done something that no parliament in the world had done and he believed it was immoral. Kevin Andrews, I was aware then and still am, is a powerfully religiously motivated man, and so I guess I understood where he was coming from. He was one of those people who believes that only God can give life and only God can take it. I

obviously have a different view to that.

I also met Kevin Andrews in Canberra. I went to Canberra at one stage while his bill was before parliament. I remember meeting quite a number of federal politicians. I had been in parliament for about 21 years by then and I knew a lot of federal politicians and had lots of conversations. It came down at the end of the day really to a very effective religiously driven group in federal parliament on both sides of the chamber.

On the Labor side it was headed by Tony Burke, who at that time was not a federal politician but he was working behind the scenes with the Labor religious networks. Kevin Andrews was doing the same on the Liberal side, and between them they were very effective.

I was heavily involved at the time, as was Philip Nitschke and a number of other individuals. I had retired by this time from parliament so we were all acting as individuals; there was no single organisation. The Northern Territory government took great exception to the bill. Then Chief Minister, Shane Stone, by the way is also a Catholic and he opposed the Rights of the Terminally Ill Act when it passed through the territory parliament. But he did all that I would expect a chief minister to do in defending territory legislation, notwithstanding that he disagreed with the legislation itself. The remonstrance originated under Shane Stone's administration at that time.

I understand, sadly, that the remonstrance which was delivered to the President of the Senate and the Speaker of the House of Representatives, which is how they are normally delivered to federal parliament, was not mentioned by a single member of federal parliament in either house during the debate, which I think is just disgraceful, at least by way of inter-parliamentary respect.

MS CHEYNE: That is interesting, Mr Perron. I am not sure if you are aware—I am sure you are keeping across all of the local ACT media—but the ACT Chief Minister has written to all but a few staunchly opposed MPs and senators calling on their support for the bill in the federal parliament, the Leyonhjelm bill, to overturn the legislation. Do you think it would be remiss if certain MPs and senators were not taking into account that letter and including it in the debate?

Mr Perron: I would hope they would. The Chief Ministers of both territories are the representatives of the citizens who live in those places and have every right, indeed, a responsibility to act on behalf of those citizens. Unfortunately, federal politicians it seems in many cases regard the next tier of government with some disdain, and that is shown in the federal *Hansard* debates.

I am pleased to say that in addition to the ACT Chief Minister, Mr Andrew Barr, the Northern Territory Chief Minister, Michael Gunner, has also made a number of statements—I am not sure if he has written to federal MPs—urging support for the bill before the Senate at the present time. Those two people have the resources of their government behind them to protest. The issue at this level is not yes or no to voluntary assisted dying; the issue is the rights of territorians to make that decision for themselves through their parliamentary representatives.

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That is what the issue is about. Unfortunately, the federal politicians in 1997, and I believe on this occasion, most of them—probably 80 to 90 per cent—will base their decision on their views on voluntary assisted dying. That is unfortunate because that is not the issue before them. A matter of state and territory rights is before them. They certainly can under the constitution overturn territory legislation, but it is whether they should. That is what it is all about. Just because you can does not mean it is right.

There are also a number of people, individuals mostly, working very hard—some of them very well-connected—on federal senators at the present time and MHRs to a lesser degree. Unless the legislation passes the Senate, of course, it will not even make it to the House of Representatives. So the concentration at the moment is on the Senate. My assessment is that there is a chance that it could pass the Senate in August. However, if it fails in the House of Representatives or the Senate, I believe this issue will be dead—excuse the pun—for many years for territorians.

MS CHEYNE: Noting that, I know you said the territory governments are doing what they can and well-connected individuals are doing what they can.

Mr Perron: I am not sure they are doing all they can.

MS CHEYNE: This is where my question is going: what else should be being done?

Mr Perron: To be honest, I have not put my hat on pretending to be a chief minister again, but this is a really serious matter in my view. Stepping back a bit, there are Canberrans and Northern Territory citizens dying horrifically, as you will have heard many times, and they will continue to die. Those for whom palliative care is of little or no value will continue to die. Probably a thousand people have died in the past 20 years who would have used the territory legislation had it stayed on foot. That is how serious this issue is. It is just ongoing.

I would think the sort of thing a Chief Minister would do who was very determined to do everything possible would move a motion in the Legislative Assembly—I am not sure when yours is sitting; the Northern Territory one will sit shortly—urging all members to physically adjourn the Assembly and adjourn to federal Parliament House during the course of debate with a view to influencing whatever federal members from across the country they could during the course of the debate starting on 14 August.

That is probably what I would try to do, and it should be supported by the whole of the Assembly, including those who may personally oppose voluntary assisted dying. The issue is not yes/no at this point; that will come at a later stage if the territories ever get the authority to do so again.

MS LE COUTEUR: That was a very interesting point, Mr Perron, that we could all go to federal parliament. Because I totally agree with your comments on the rights of the territories I was not going to spend a lot of time on that, and my fellow committee members have already prosecuted that.

There has been discussion that if some jurisdiction does it they will be swamped by people wanting to go there to die. Given that the Northern Territory was the first in

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the world—admittedly it was a fairly short period—did that seem to you to be an issue? Were people thinking about coming to the Northern Territory just for access to—

Mr Perron: In hindsight it was probably a mistake that the territory did not include a residential status for people to be eligible for services under the Rights of the Terminally Ill Act. The reason we did not put in a residential status at that stage was that the motivation for the legislation was one of compassion, for relieving suffering. If a person visiting the Northern Territory as a tourist or in some other form took ill and was in the hospital or otherwise unwell and eligible for assistance alongside a Territorian who also had the same condition—you can see where I am going—it would be wrong, morally, to say to one patient, “We can assist you”, but to the other, “No, I’m sorry; you’re Japanese or a Queenslander or whatever and you’re not going to be helped.” So we did not put in a residential qualification.

That probably aggravated the Kevin Andrewses of the world more than anything, the fact that people from interstate could go to the Northern Territory to be assisted. They really made the point that we had legislated for the whole of Australia. The fact is that of the four people who took advantage of the Rights of the Terminally Ill Act three were from interstate and one was from the Northern Territory. Of those from interstate, two were from New South Wales and one was from South Australia, both places, by the way, where there were adequate palliative care services. These people were still prepared in their desperation to go to the Northern Territory to be assisted.

Subsequent to that virtually all of the jurisdictions that have introduced VAD have a residential requirement, including, of course, Victoria. I think that is reasonable for them to do that. It will apply pressure on the adjoining states—New South Wales and South Australia—and others through people asking, “Well, why should I have to go to Victoria and set up to become a resident and stay there for however long I need to comply with the Victorian legislation? This is nonsense. Why don’t New South Wales have this legislation?” Of course, one day we might see New South Wales with the legislation surrounding everyone in the ACT who will not have eligibility.

THE CHAIR: Thank you so much for your time today, Mr Perron. When available a proof transcript will be forwarded to you to provide an opportunity to suggest any corrections.

HOGAN, ADJUNCT PROFESSOR ANTHONY

THE CHAIR: I welcome our final witness for today's hearings. Adjunct Professor Anthony Hogan. Can you confirm for the record that you understand the privilege implications of the statement in front of you?

Prof Hogan: I have read it and understand it, thanks, Madam Chair.

THE CHAIR: Thank you. Would you like to make a brief opening statement?

Prof Hogan: I would, thank you, Madam Chair. I am an adjunct professor in sociology and research at the Practical and Contextual Theology Centre at Charles Sturt University, and I am an adjunct honorary professor in public health at the University of Sydney. I am also working in conjunction with a research company whose data I am using today, Instinct and Reason.

This research company, which has an interest in public good, conducts quarterly surveys. They colloquially named them the "boomers" and the other one the "millennials". They routinely survey people on a bunch of questions about happiness with life, household insurance, investments and so forth. Each quarter they do what they call a deep delve and they open it up to people such as myself to suggest themes and questions. We have done a series of them over time; some of you would know my interest in hearing loss, which is one of the ones they have done.

Given the events in Victoria of recent times, it seemed that posing questions on the issue of voluntary assisted dying would be of interest to our survey people. We consulted with the community group Dying with Dignity and got permission to use their question. The survey was fielded by the market research company earlier this year with a sample of 2,000 people equally between the millennials and the boomers.

The study was also motivated by the plebiscite on same-sex marriage, given the religious divisions that were around it at the time and the way the vote played out. As a social researcher I was intrigued as to whether the same dynamics existed around this issue given that church authorities spoke strongly against this kind of legislation. I was interested to see what, as they say, the people in the pews thought.

We have nationally representative samples with good controls for error margins. As I said, we have used previously fielded questions. The results have been reviewed by peers in the field, and we have very nice feedback from those folks. The results of this study is consistent with studies conducted in Australia and overseas.

In summary, the survey shows very strong community support for voluntary assisted dying, when a person's condition is terminal or pain is unbearable and all other options have been exhausted. Thank you, Madam Chair.

THE CHAIR: Thank you. You said the sample size was about 2,000?

Prof Hogan: Yes, each of the samples was 1,000. Typically when someone like Newspoll goes to test the voters' instincts, it is around about 1,000 to 1,200 people.

With any sample over about 500 your error rate gets quite low in terms of whether the number wobbles. By the time you get to 1,000 the numbers do not wobble very much and increasing that sample size above 1,000 is basically a waste of money because you are not going to change the insight you are going to get. If I could draw attention to some of the pages in my report, tables 1 and 2 provide a summary of the representativeness of the populations participating in the study. They are reasonably close to the spread of jurisdictions as you would expect.

We did not specifically study the ACT but we would note, particularly again from the same-sex marriage studies, that people's positions on these issues shift in terms of the community's level of education. We know that the ACT population has a much higher level of education than the rest of Australia, generally speaking. So we are one per cent of the sample in this case.

THE CHAIR: If there were to be a more direct sample size taken just from an ACT perspective you believe that a sample size of between 1,000 and 2,000 would be a relatively strong indication of the community view?

Prof Hogan: Yes, that is typically the survey size you would go to field with. It is basically about how much random error happens. At that level statisticians are very comfortable that you do not get the statistical wobble.

THE CHAIR: The one per cent and the two per cent for the millennials, that is about five people in total?

Prof Hogan: In the ACT, probably.

THE CHAIR: Sorry, it is so I can get a concept in my brain, that is all.

Prof Hogan: We go nationally, so I did not try reduce it down to the ACT. With a number of one per cent, you are going to get wobble. That is just how it is, it is not a big enough sample. But we can go back to the previous point that the data is very consistent nationally and internationally with other findings. You would be amazed if you did another sample in the ACT and it came out differently. You would actually ask why, I think.

MRS DUNNE: Could you run the committee through the questions?

Prof Hogan: Sure. For your information, the questions are appended to the submission.

MRS DUNNE: Yes, but just for the record.

Prof Hogan: Of course. Question 1 is: what is your view on euthanasia? People were given three fixed choice options: it should be legalised; it should not be legalised; and uncertain.

MRS DUNNE: Was there any preamble?

Prof Hogan: No, I do not think there was.

MRS DUNNE: So it is a cold question?

Prof Hogan: Yes. We would have asked a series of questions about, “On a scale of 1 to 10 how would you rate your satisfaction with life today,” and then, “What is your view on euthanasia?” So we would not contextualise it because that would be leading people’s responses.

I will correct myself, Mrs Dunne—it may have said, “Now we are going to ask you a series of questions about ...” That would be as far as it went.

MRS DUNNE: Could you check that?

Prof Hogan: Absolutely.

MRS DUNNE: And also, just for information, before the question on euthanasia, what was the previous set of questions about?

Prof Hogan: Sure.

MRS KIKKERT: Are you able to table the survey with the questions?

Prof Hogan: Absolutely. Yes. The whole survey?

MRS KIKKERT: Yes.

Prof Hogan: Absolutely. From memory, looking at the data in my head, there was a series of questions of “How likely are you in the next five years to: take an overseas holiday; buy a house; restart education?” It was completely left field to this set of questions.

MRS DUNNE: Yes, okay.

Prof Hogan: But I take your point. The other seven questions were: on a scale of 1 to 5 from strongly disagree to strongly agree—and allowing for “Don’t know/not sure”—how strongly do you agree or disagree with the concept of allowing assisted suicide means people can die with dignity; euthanasia should be legalised for anyone who wants to end their life; everyone has a right to decide when they want to end their life; euthanasia will desensitise people towards death and will result in devaluation of human life; drafting laws will not solve the ethical issues regarding euthanasia; euthanasia is an acceptable solution for people with terminal or extreme physical illness; and euthanasia should only be used in certain circumstances if legalised in Australia.”

MRS DUNNE: So they were the follow-up questions.

Prof Hogan: Yes, and this was done as an online survey, so their presentation would have been randomised. There was no opportunity for people to get into a flow of tick, tick, tick, tick, tick. Each presentation would have been in a different order, again to deal with issues of respondent bias.

MS CHEYNE: Noting that your survey was national—and we did talk about the small sample size for the ACT but, of course, that was representative of the population size—do you think there would be value in the ACT holding its own survey or do you think the survey you have done is statistically relevant?

Prof Hogan: As an academic always in search of research funds, one might cynically say, “Well of course we need to do more research.” I think, practically, the result would not change; I do not think there would be new insights coming forward from this kind of study given how consistent it is. One of the findings which was interesting was regarding what we refer to as the non-sandstone Christian churches, and they were more likely to not support such legislation. That is the same finding as in Canada in the same kind of proportions. So I would be delighted to take some funding to do the survey. I do not think it would help in terms of providing depth of insight.

MS CHEYNE: So you do not think there is anything different at all about the ACT or its population make up or—

Prof Hogan: I do. I think they would more strongly support the outcome given. If the principles that I took from the same-sex marriage surveys and plebiscite outcome and the analysis done by colleagues out of Latrobe University were to hold—that education is strongly correlated with, say, support for same-sex marriage—given the ACT’s demographic profile I would theorise that people would be more strongly in support of it than they presently are.

MS CHEYNE: I note that religious perspective, depending on the denomination, affected people’s views. Do you think that applies in the ACT? Is the ACT more secular?

Prof Hogan: No, I do not have a view on that. One of the things the data show, though, is that support or participation in the churches is more associated with older age. In some senses we are a younger jurisdiction, so that may have an influence.

MS LE COUTEUR: You asked questions of boomers and millennials, but clearly there is a bunch of people in the middle. Was there a reason they were left out? Have you any reason to think their views would be in any way different?

Prof Hogan: The research company has been running these omnibus studies, as they call them, for commercial purposes, and I am the beggar who gets questions in for free. But it does stand out as an issue for this company that there is this big group in the middle that they do not know about in terms of all the issues they are studying. They do a lot of this stuff pro bono so it is a commercial decision for them.

But coming back to Ms Cheyne’s point, that is the part of the sample we do not know the views of. The thing we know nationally is that the proportions of people participating in all the churches is quite rapidly going down. This is not a unique phenomenon to Australia either; be it Latin America or other countries, the demographic is shifting away from participation in the churches.

MS CHEYNE: Do you think over time we will see support for voluntary assisted

dying grow as a result?

Prof Hogan: Yes. When you look at the data there is a group who identified themselves as religious, and groups who identified as spiritual, agnostic, and atheist. There is support or uncertainty in the religious group, but as soon as you move out of that group they are very strongly supportive of support for euthanasia. Again, when you look at the millennials compared to the boomers, the numbers participating in religion are again less.

What is really interesting in the study is that people get to write comments, which are always really interesting. One young person wrote, “Like, why are you even talking about atheists?” It is just not a concept we even relate to today. It is like we are beyond whatever atheism and theism were about. It is just not on the radar for a group of them.

MS CHEYNE: I think why I am so interested in the applicability of your study to the ACT in particular is because in this inquiry, as you know, we had a record number of submissions. Different groups encouraged different people to submit. We have heard consistently that support in the ACT and nationally is around 80 per cent. But based on our submissions it was a lot lower. What is of interest to me is whether the submissions are necessarily representative of the broader population and whether a broader survey or poll is required.

Prof Hogan: It is a good point. Our data shows that people who are against such legislation, whilst smaller in number, hold their views far more strongly. Can I hold up a graph? I do not know whether it is going to help at all. On graphs like this, this middle part represents average views, and the higher a line goes above or below the line is how more strongly the views are held.

This is, for example, the millennials group against, and they quite strongly hold their views. You will see the same thing with the boomers. This is the boomers against. Look how long those bars are compared to the ones for or conditional. They go, “Yeah, that’s okay. I’m not going to get too upset about it. But I think this is, like, what the case might be.” Whereas the against is, “I am very strongly holding my values and am asserting them.”

MS CHEYNE: And I am going to be more vocal about it.

Prof Hogan: Yes. But when I break up the data and get the stats to clarify between the people who are sitting on the fence, the strongly held values are 15 per cent of the population. So they are loud and they are vocal. I think Paul Keating had a phrase that summed up perhaps the electoral view of their representativeness.

MS CHEYNE: Which is very funny given Paul Keating’s own view on the subject.

Prof Hogan: Yes, exactly.

MS CHEYNE: Do you think it is likely that the submissions we have received are skewed?

Prof Hogan: I have not reviewed them to be honest. But there is passion in this data and there is ambivalence in this data. To reiterate the point, those against it are strongly against it and you could mobilise people around that. Similarly with the same-sex marriage debate, when it comes to a public expression of position, these data will play out. The millennials are coming in at about 65 per cent or 60 per cent support and the boomers are coming in at 90 per cent if the question is tightly framed: it is clarity; it is voluntary; it is end of life; all has been done; nothing more can be done; and “I consent to this process”.

What this data shows in particular is that some of the questions were not tightly framed and people said, “Oh, I’m not really sure about that. I want more information before I am prepared to say yes or no.” They are worried about it being an elastic piece of string.

What was interesting in terms of the religious perspective is that we saw far more cultural diversity in the millennials in terms of Asian religions—Muslim perspectives—than we did in the boomers. It would be interesting to have data on the middle group because they are kind of in between the two in terms of the demographic spread. I think the older group was a far more white Anglo-Saxon demographic in terms of who came forward in the data. So there may be differences there.

The other question may be in terms of over sampling. In the ACT example, for your purposes you would want to pump up that number to have a sizable number that you were happy with and then also across the three groups to give you the comfort you are looking for in the data. I am still going to suggest the result will be the same.

MS CHEYNE: But it might be helpful.

Prof Hogan: Politically helpful I think in terms of people being clear on the ground and feeling confident and feeling safe. I think what this data is saying is that the community wants to feel safe about this. They want to know that going forward it is a safe process for the people affected.

MRS KIKKERT: You said that 2,000 people participated in the survey?

Prof Hogan: Yes.

MRS KIKKERT: How did you find those 2,000 people? Was it just a random finding?

Prof Hogan: These days the various research companies have online research panels. Invitations are randomly generated to these panels and then the panels are quota based. So once the quotas are filled they are closed. We want a population distribution of New South Wales by gender, age and so forth, and once that number is filled from that part of the segment no more of those people can participate. In a survey of 1,000 the first 600 or 700 boxes fill pretty fast and then it takes a few more days for the rest to come in. So it is all random. There is no communication. There are no relationships with the participants.

I do not know how the particular sample base in this case is rewarded. Some get shopping points. I do not know what the incentive is to be on these panels. In the early days, like 20 years ago, the panels were unreliable because they were small and self-selected. But today I think everyone uses them and they are quite reliable.

THE CHAIR: So your main role in this was to analyse the data collected?

Prof Hogan: Yes, I am a data junkie. I analysed the data and wrote it up. Given that you were conducting this inquiry I thought it convenient to share the data with you.

THE CHAIR: And it has been fabulous. Having you here today has been quite interesting for the committee.

MRS KIKKERT: Did you participate in forming the questions for the survey or is it just the data collection that you participated in?

Prof Hogan: It is a moot question. We consulted Dying with Dignity for permission to repeat their question. I drafted questions for the research company in their list and they changed some of them. They could have been tighter. But tighter is boring and tighter is difficult in terms of research clarity. The questions that went to field were not the ones I exactly drafted. Again, beggars can't be choosers. The person fielding the study decided to phrase these additional questions in the way they did. Again, I am at arm's length from the whole research process. Someone said, "Would you do it? I've got the data," and then I have analysed it and written it up given my academic interests.

THE CHAIR: You suggested that the tighter the question the better the data or the more reliable the data?

Prof Hogan: Yes, people want to know what they are agreeing to. People want to know what is going to be legislated. They want to know that it is voluntary. For example, one of the questions is does a person have the right to die at any time? The data is quite distributed: some people say yes and a lot of people say no, that you do not have the right to die. But this inquiry is about end of life assisted dying and that it be voluntary. In relation to your question, Mrs Kikkert, even though I consulted the group, as one of the stakeholders in their feedback the question should have been, "What is your view on voluntary euthanasia" to tighten up that question. If we were to run it again I would tighten the question in that way.

It is a highly contextualised decision we are making here. We are not saying that you can go into your GP and get a script for whatever it is you take to kill yourself. We are not talking about that; we are talking about assisted dying when you are terminal and extreme in the sense of nothing else can be done to help you.

MRS KIKKERT: So what was the question as it stood?

Prof Hogan: What is your view on euthanasia?

MRS KIKKERT: But you would change it?

Prof Hogan: To: what is your view on voluntary euthanasia? More specifically, I think the best question is: is voluntary euthanasia an acceptable solution for people with terminal or extreme physical illness? Again, the Canadian and others have been down this road and have better-worded questions.

THE CHAIR: If we have further queries, are you happy for the committee to contact you?

Prof Hogan: Yes, shoot me an email, ring me up, whatever. And I am happy to reanalyse the data through a different lens if you see one.

THE CHAIR: Thank you. As we have heard from other witnesses today, the ACT is unable to make legislation in regard to assisted suicide, and there will be a bill on the subject introduced to federal parliament shortly. Do you think that that will change the data at all or should that not even come into the question about voluntary assisted dying?

Prof Hogan: I do not think it is on people's radar.

THE CHAIR: I am talking from a data perspective and clean, clear data.

Prof Hogan: I do not think people are thinking about whether or not the Andrews bill is in place. This is people's view on: do you think this should happen? I did not analyse things by jurisdiction, but the data is weighted by jurisdiction, by population. You would not run it by ACT because one per cent, you know, it is just going to all be noise. It is too small.

THE CHAIR: Thank you very much for appearing today. If witnesses undertook to provide further information or took questions on notice during the course of the hearing, whilst the committee has not set a deadline for receipt of responses, answers to these questions would be appreciated within two weeks from the date of this hearing. When available a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections. I now close today's hearings.

The committee adjourned at 11.01 am.