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

TRANSCRIPT OF EVIDENCE

CANBERRA

THURSDAY, 31 MAY 2018

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

By authority of the Legislative Assembly for the Australian Capital Territory

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WITNESSES

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Amended 20 May 2013

The committee met at 9.18 am.

ILES, MR MARTYN, Managing Director, Australian Christian Lobby
TAYLOR, DR ELISABETH, Director, Research, Australian Christian Lobby

THE CHAIR: Good morning, everyone, and welcome. I declare open this fifth public hearing of the Select Committee on End of Life Choices in the ACT inquiry into the matters referred to the select committee by the Legislative Assembly on 30 November 2017.

The proceedings are public, are being recorded by Hansard for transcription purposes and are being webstreamed and broadcast live. Before we begin can I remind witnesses of the protections and obligations entailed by parliamentary privilege and draw to your attention the pink privilege statement which is set out on the table in front of you. These are important.

Before the committee starts the hearing part of our program today, on behalf of the committee I acknowledge that we are meeting on the lands of the Ngunnawal people, the traditional custodians of the land. We respect their continuing culture and the unique contribution they make to this life, this area and this region.

I welcome today's first witnesses, from the Australian Christian Lobby. Could you confirm for the record that you understand the privilege implications of the statement in front of you?

Mr Iles: Yes, I do.

Dr Taylor: Yes, I do.

THE CHAIR: Before we proceed to questions from the committee, would you like to make a brief opening statement?

Mr Iles: I surely would, yes. My thanks to the chair and to the committee for the opportunity to appear today. The Australian Christian Lobby is a grassroots movement of over 120,000 Australians, nearly 2,000 of whom reside in the ACT. We exist to represent and amplify the voice of our constituents into the political process and the public sphere more generally.

The ACL has argued against the introduction of assisted suicide laws in every Australian jurisdiction where they have been proposed because we believe in the inherent dignity of all human life regardless of age, ability, gender or status. Euthanasia overturns the sanctity of life. It says that some lives can be ended with state approval because they are not worth living.

But the question arises: not worth living according to whom? Elderly lives? How elderly exactly? On the question of terminally ill lives, how long should they be expected to live? Six months or one day or 12 or 18? Is it for physical suffering only or does that stigmatise mental illness? Should mental suffering also be included? What of terminally ill children suffering heart-breaking pain?

We know that once it is legalised these very arguments for liberalising assisted suicide laws persist and there is no logically unassailable principle with which to draw a line in the sand. The problem has been thoroughly proven especially in those jurisdictions where assisted suicide laws have existed the longest, and I can give you some examples.

A young Belgian woman with borderline personality disorder was euthanised in 2012 at the behest of her parents. She was not suffering depression but she was deemed to be suffering inasmuch as she found it impossible to have a goal in life. She was 25.

Mark Langedijk was euthanised at the age of 41 in 2016 because he struggled with alcoholism. His brother described how Mark sat on the bench in his parents' garden eating ham and cheese sandwiches and soup with meatballs until the doctor arrived at 3.15 pm. He drank a glass of wine and smoked a cigarette but turned down a second because, as he said, "I'm dying now."

The Dutch case of Mrs De Troyer was recently referred for a second time to the European Court of Human Rights. She was euthanised at 64 because she was depressed. Her treating doctors were not persuaded that her depression was incurable but she found others who were willing to certify that it was. Her son unexpectedly learned of her death whilst he was at work.

The Dignitas Clinic in Basel euthanised Magistrate Pietro D'Amico because he had been diagnosed as terminally ill by three doctors. However, a subsequent autopsy revealed that the diagnosis was entirely incorrect. Wrong diagnosis affects five per cent of outpatients in the US, amounting to 12 million mistakes every year.

Forty-five-year-old twins Marc and Eddy Verbessem were blind and, upon hearing that they would go deaf, they obtained euthanasia in 2013 believing they had nothing left to live for. The same year a 44-year-old was euthanised after botched sex change surgery left her looking, in her words, "like a monster".

Last year in Holland a doctor had sedated an elderly female patient by drugging her coffee but whilst the lethal drip was inserted the patient unexpectedly rallied and began to struggle. The doctor called on the patient's family to hold her down while she was killed. A subsequent investigation found that the doctor had crossed a line and should not have proceeded but had not broken the law.

The year before, a woman was euthanised for mental suffering stemming from her history of child sexual abuse. Last year in Belgium an elderly woman was euthanised without having requested it at all. The decision was made for her by her family. A 2015 Belgium report indicated that this was not an isolated case. One in 60 deaths under a GP's care in Belgium now occur without an explicit request from the patient.

Deaths from misdiagnosis, deaths for depressive illnesses, deaths because people are tired of life, convenient deaths carried out by what is now a mobile euthanasia service in the Netherlands, deaths of the disabled, deaths because of elder abuse and social pressure to stop being a burden—I opened by pointing out that pressure on all these particular points and more is applied under assisted suicide regimes to liberalise the laws for years to come. Overseas experience does prove it and I could keep you here all day with examples.

Professor Theo Boer, who was once a strong euthanasia advocate in the Netherlands, after reviewing 4,000 cases, concluded that he had been wrong, terribly wrong in fact, to believe that regulated euthanasia would work and elsewhere he remarks that some slopes are indeed slippery.

I look forward to your questions.

THE CHAIR: I have a couple of very quick questions for you and then I will pass to Mrs Dunne because I am sure she has lots of questions. With the cases you cited in your opening statement, was it their own choice—possibly the last one, maybe not—to take their own lives?

Mr Iles: On the whole, yes.

THE CHAIR: And none of those cases were Australian based? They were in other jurisdictions where voluntary assisted dying is legal.

Mr Iles: Yes, of course, because there is no jurisdiction in Australia where—

THE CHAIR: I just wanted to make sure that I was—

Mr Iles: Just a comparison.

THE CHAIR: I just wanted to make sure I was understanding the context of your opening statement.

Mr Iles: Sure.

MRS DUNNE: Mr Iles and Dr Taylor, I want to explore with you the notion that in Victoria we have legislation, which has passed but not commenced, and we are told there are endless numbers of safeguards and that the sorts of things that you have described as happening in Belgium and elsewhere could not happen under the Victorian legislation. Would you like to comment on that?

Mr Iles: My colleague will go into more detail than I but, from the examples that I cited in the opening statement, I talk about the case of Mrs De Troyer, who had two doctors who were not prepared to say that her depression was incurable and so she went essentially doctor shopping until she found somebody who would say it and did indeed administer the euthanasia. And that was the case where her son, Tom Mortia, who is now a vigorous anti-euthanasia campaigner, found out about her death completely without notice, unexpectedly, while he was at work one day and he had to go and make arrangements to sort out the body.

But that possibility is well and truly open in Victoria in the sense that you need the say-so of two doctors but they do not have to be your doctor and it does not have to be a palliative care specialist. It does not have to be a psychological specialist. It is just two doctors.

MRS DUNNE: I see your point about doctor shopping but depression is not an illness that is allowable under the Victorian legislation, is it?

Mr Iles: Sure, and the same thing was true in various regimes around the world where they start at a certain point. In Belgium, for example, and the Netherlands there was not any provision for euthanasia of young people. But 14 years or 12 years after the euthanasia laws were introduced in Belgium it has expanded to young people—children of any age. In the Netherlands it has expanded to children 12 and over. There is an advocacy now for children under 12.

The point of the opening statement was that once the euthanasia laws are introduced there is pressure on each of these points. In fact the argument in Belgium was that restricting it to physical suffering stigmatises mental health. Mental health is as valid as physical health complaints and therefore that unendurable suffering that is from mental health should also be included. Of course, it is a hard argument to resist, as are the others once the precedent has been set.

The point here is that the pressure applies on all those nodes once the laws are in place and that has happened around the world. There is no reason at all to assume that it would not happen here. I do not know if you have any comments.

Dr Taylor: You mentioned depression, and that is quite an important point to note because depression frequently follows a diagnosis of a terminal illness.

THE CHAIR: Not always.

Dr Taylor: Not always no, indeed, but in a lot of cases. Depression can be very difficult to diagnose, particularly without a psychiatrist involved in the process that is in place in Victoria or proposed for Victoria.

Also there are no palliative care specialists. On GPs, it has been revealed in the course of the investigations for Victoria that a lot of palliative care specialists particularly from New South Wales were saying that they were concerned that the level of education about the possibilities of palliative care among the GP population was very low. When GPs are not in a position to advise their patients sufficiently on the possibilities that are available through palliative care and then when there is no psychiatrist involved or psychologist involved, who would be able to diagnose where depression is a confounding factor in the patient’s reaction to that diagnosis? And both those things create vulnerabilities where a patient might choose euthanasia in a depressed mental state or where the possibilities and other options may be insufficiently explained to them even by the GPs.

MRS DUNNE: Thank you for that, Dr Taylor. One of the things I am trying to get to, Mr Iles, is this: is it the contention of the Australian Christian Lobby that everyone starts with good intentions of keeping a tight rein on this, but that there are inexorable pressures? In other jurisdictions like those in the Low Countries, has that inexorable pressure manifested itself in legislative change, administrative change or both that has led to what seems to be an expansion of access to assisted dying?

We have seen, for instance, that there are some figures out there that indicate this starts off at a very small proportion of the population but grows quite rapidly arithmetically over a short period of time. Is the contention of the Australian Christian Lobby that if you start, you cannot put it back into the box at all and that the only way is to expand the program?

Mr Iles: There are probably two things. The first is that whatever the laws are, including the Victorian example, there is no way to prevent abuse or error. So it is not only that there are inexorable pressures and that is the problem. That is a problem. But there is a problem with the regimes themselves in that it is not capable of making them free of abuse.

The first one I mentioned was doctor shopping. The other one is just diagnosis. I said in my opening statement that five per cent of outpatients in the US are affected by misdiagnosis; 12 million mistakes a year. In fact, Dr Stephen Parnis, the former President of the AMA, in speaking to this very issue, said that—

THE CHAIR: Former national president or—

Mr Iles: I think that is correct. He said that diagnosis for six-month and 12-month time frames is notoriously difficult, even for highly experienced medical professionals. There is quite a large number of examples in our submission of diagnosis time lines of 12 months, six months, that just came out to be completely wrong. People have lived up to 20 years after the fact.

There is also the issue of the drugs themselves. People often say, “Roughly three per cent of people die in pain because of improper access to palliative care or the shortcomings of palliative care.” But it looks like about three per cent of people who receive a dose of lethal drugs under euthanasia are also dying in pain and distress because the drugs are not fail-safe. There are plenty of cases where people have come back to consciousness, have experienced great distress and have died slowly. It is roughly three per cent. You do not really get that issue. There is a range of issues that arises straightaway as soon as you set the principle.

There is also the problem of when the changes come. The changes are twofold, as you have said. Firstly, there are legal changes and policy changes. But, secondly, there are just changes in practice. It seems that a lot of these cases come from both of those categories. The fact that one in 60 deaths under the care of a GP—euthanasia deaths—occurs without an explicit request from the patient is just a change in practice. There was this survey done—my colleague might have the specific details of which one—that showed that it may be as low as 18 per cent of euthanasia deaths in Belgium are now actually reported.

The other side of it is that the uptake of euthanasia increases rapidly. So between 2008 and 2013 there was a 250 per cent increase in the uptake of euthanasia, again in Belgium. Similar very strong upward trajectories are seen in other nations. In the first few years it tends to be very flat. It is something that is not taken up by many, but then the increase comes.

There was a UK House of Lords debate on euthanasia. There was anecdotal discussion there about elderly people. I have heard this also around the traps at conferences and things. It is of elderly people who carry cards saying, “I do not want to be euthanised,” because it is now such a thing. There are stories that are getting around of people that have been euthanised under circumstances of dementia and so forth. There is the practical—

MRS DUNNE: This is in countries—

Mr Iles: This is in the Netherlands.

MRS DUNNE: in jurisdictions where there are legislated regimes.

Dr Taylor: Yes.

Mr Iles: Yes, exactly. Those are all changes that are specifically legislated. They are changes in the way these things are done. There are advocates on the various euthanasia review boards and so forth as well that continue to say things. Who is the president of the one in Belgium—the guy who says that people—

Dr Taylor: Distelmans.

Mr Iles: That is right. Distelmans is his name. He is the president of the review board in Belgium. He, for example, says things like if people are lonely then we cannot create family for them; so that is incurable suffering and so euthanasia is a valid way. There is a quote from him in our submission to that effect. So you have the advocates as well.

Then you have the legislated changes. For example, the legislated changes come in the form of expanding to children or expanding into mental health—things like that. Those arguments, when they are raised, are very hard to resist. Once you get terminology into the legislation that is sufficiently flabby around incurable suffering—that kind of wording—the application of that is potentially very broad.

Distelmans, for example, is saying that lack of family is incurable suffering because we cannot create family; or for various mental health issues—depression that just will not go away. On the one hand we offer suicide hotlines. On the other hand, if it will not go away, we will provide assisted suicide.

Once the language is sufficiently flabby, that really opens the floodgates. But the pressure to get that language in only continues. In fact, in Australia, with the 104-year-old academic from Perth that went over to Switzerland, the only reason he sought euthanasia was because he was tired of life. The principle there is that he is elderly, tired of life, he does not feel he has anything left to live for. If that principle is to be accepted then there will be the same situation and people will be seeking euthanasia for all manner of reasons.

Dr Taylor: I wanted to add one thing to that, which is that the pressure on doctors comes through this as well to make a decision where the family thinks it is in the best interests of their elderly family member. There is a case that we quote in our submission of a doctor in Holland. He was diagnosed with a terminal illness and he wanted to die at home. His children refused to support him if he did and to look after him in the home.

In any case, the government decided that they would support him and a social worker was sent then to have a look at the household. They found that it had been entirely cleaned out by the children, who meanwhile had threatened to sue the doctor if he did not euthanise their elderly father, who was terminally ill. That case is a clear case of elder abuse and the doctor himself was subjected to the threat of legal repercussions if he did not adhere to their wills.

There is another survey of doctors, again in the Netherlands, where 800 record being subjected to pressure from families. It is not just a pure clinical medical decision that is being taken. It is being taken in complicated circumstances. Where this is an option, the pressure comes from all sorts of different angles, not just through the pure autonomous agency of the elderly or terminally ill person themselves.

Mr Iles: There was also a study in Oregon. There was the one in Belgium and there was another one in Oregon in 2012. It says that 57 per cent of patients reported burden to family and friends as an end of life concern. A similar study showed only about 28 per cent actually said that inadequate control of pain was a concern.

MS CHEYNE: You have used a lot of examples this morning. I am not sure if you have seen some of our previous witnesses or hearings, but something that is really important to the committee as a whole is that we make sure we are not, from both sides of the debate, focusing on sources which might be skewing things. Even last week we had one witness present a source that had been widely discredited and that turned out to have made-up statistics. On notice, are you able to please provide the sources for the examples that you have used today?

Mr Iles: Yes, absolutely.

Dr Taylor: They are all in our submission.

MS CHEYNE: That is great, but if you could just highlight those for us, that would really help.

Mr Iles: Sure; no worries.

MS CHEYNE: I am particularly interested in the one about Belgium, I think, which has been quoted a few times: that one in 60 deaths occurs without consent. I am very keen to hear about that.

Mr Iles: Yes; that is fine.

MS CHEYNE: This is a bit off topic, but perhaps, with indulgence, I might be able to get two questions in. I was interested in the Australian Christian Lobby’s use of a survey form.

THE CHAIR: Due to the privileges inquiry, I do not know that we can go down that line of questioning, Ms Cheyne.

MS CHEYNE: Why not? It is directly relevant to our inquiry.

MS LE COUTEUR: It is relevant to our inquiry.

MRS DUNNE: No, I am sorry, but it is not.

MS CHEYNE: It actually is.

MRS DUNNE: It is, and it would have been, except that it is now subject to a privileges inquiry. If there were not a privileges inquiry, I think you would be perfectly free to ask about it.

THE CHAIR: I understand where you are going with this question. What I would like to do is seek some advice and then possibly provide the question on notice if the advice comes back that we can continue down this line of questioning.

MS CHEYNE: Sure.

THE CHAIR: Sorry, Ms Cheyne.

MS CHEYNE: I know Ms Le Couteur is very interested as well.

MS LE COUTEUR: It is significant.

THE CHAIR: I understand that. I note that there is currently a privileges committee inquiry looking into this exact matter. I do not want to bias the privileges committee by asking questions in here. I know that in other hearings when we have crossed over the line with things that are not quite as fine, there has been pullback. I would just like to seek advice.

MRS DUNNE: I would agree with that.

THE CHAIR: If the advice is that you can ask the question, could you possibly provide it on notice if we run out of time before the advice comes back?

MS LE COUTEUR: Clearly, we are going to run out of time.

THE CHAIR: I understand that. I tried to seek advice on this matter yesterday; I was unable to seek that advice. I would really like to seek that advice before we continue.

MRS DUNNE: I agree with that. That is a good approach.

MS CHEYNE: You make the argument that we can never legislate for every possible risk and therefore we should not legislate at all. Can you expand on that a bit for me? We could apply the same argument to many things, like allowing people to take drugs that are addictive but are on prescription. To say that we should not allow anybody to use those drugs because we could never legislate for an absolutely perfect system seems like bad policy to me, and I am sure we could find numerous other examples. Are you able to expand on that for me? I think that the heart of your submission is about the slippery slope and not being able to make this a perfect system. But in relation to policy, perfect is often the enemy of the good. I am keen to learn more about that.

Dr Taylor: I will answer that question, if I may.

Mr Iles: Sure.

Dr Taylor: I am not sure I understand the analogy with taking drugs, but in this case the consequences of misapplying well-intentioned legislation is life and death. It is a very serious consequence, and therefore it needs to be considered much more carefully.

If you take another analogy, the death penalty, if you asked the population about whether they supported the death penalty, the general answer would be that they were against it, primarily because we can never be absolutely certain that we have administered justice correctly. There are very many cases, and Amnesty International will quote them, of people who have been released from death row, even in the last year, having been sentenced to death and subsequently found to be innocent of the crimes for which they were convicted.

That is a legal process. It is a very open process. It is subject to a high level of public scrutiny and record keeping. In this case, this is a very different situation in which none of those processes are possible, none of that recording. It is not possible to go back and review every medical case and examine the witnesses. It happens behind closed doors with a patient and two doctors. Because it is not subject to the same level of public scrutiny, we can anticipate that the risks in this case are much greater.

I understand completely why there are people who would wish to have this available as a choice. What I do not understand is how that choice can be granted without increasing disproportionately the vulnerability of people who are already very vulnerable.

MS CHEYNE: Are we not at the moment doing a disservice to people who are already very vulnerable? I completely appreciate the many examples you have given today, but I think we have heard, and will be hearing, of other examples where many people have unduly suffered, and how long the flow-on effects and psychological effects, both for them and their broader family, have lasted. The broader societal effects of that are also very significant. Doesn’t the argument go both ways?

Dr Taylor: It does. I can understand that the suffering is very real. What is different is that the government has not commissioned that suffering in a way that it would have, by a relaxation of these laws, commissioned the death of other people who died when they would not otherwise choose to die. In that sense, the suffering is very real on this one hand, but it is not a result of a government policy, whereas the unintended deaths of people who are already vulnerable—and we have seen in the international example that this happens, that people die who otherwise would not die—would be directly resulting from a relaxation of the government’s policy in this area. That was one of the things that I wanted to say. I am sorry, I cannot remember—

Mr Iles: Do you want me to add something while you think?

Dr Taylor: Yes, please.

Mr Iles: If there is a problem in this regard, taking what Dr Taylor has said, there are also two potential solutions. One is to invest further in medical care according to existing principles of medical care, the "do no harm" principle, which is palliative care. Experts in palliative care clearly say that, properly resourced, there is no need for people to be dying suffering horrendous pain, because palliative sedation is always a final option for that very small number of people who find themselves in this circumstance. So you can either put—

MS CHEYNE: We have also consistently heard evidence from a range of medical practitioners that in a small number of cases, and it is small, palliative sedation is not enough.

Mr Iles: And if you take the small number of cases of which you speak—I am not an expert in the field so I just take what they say—and you compare it with the suffering and pain inflicted on the small number of cases where euthanasia is not as effective as it ought to be, where there are adverse reactions to the lethal drugs, where people regain consciousness or undergo distressing episodes, there is no net gain on either side. About three per cent, I think, of euthanasia patients experience death in distress because the drugs have not worked or something else has gone wrong. For the stats on palliative care, I think it is two per cent in Australian conditions.

Dr Taylor: Between two and four are those statistics.

Mr Iles: Between two and four, so it is about the same. So it does not actually remove the problem for that small number of people. There is always a small number that will suffer.

Dr Taylor: You were also mentioning the distress to the families. My father died of cancer a couple of years ago, so I am familiar with the situation of families watching a close family member dying slowly. One of the things that I think is very interesting is the situation from Switzerland. There is some research that suggests that families who watch a loved one die through the process of euthanasia often suffer from post-traumatic stress disorder or complicated grief. I think there is a misconception that euthanasia is a silver bullet, the answer to everybody's suffering. I think that that needs to be challenged.

MS LE COUTEUR: Dr Taylor, you said that suffering was not government policy. I was going to discuss that, but I did not really have to because I think your colleague basically put the point fairly clearly: many people are suffering because they are not getting the palliative care that they could get. It is a very big subject, but simply to say that people suffering is not government policy, given the limitations of better health funding, social services funding et cetera, is probably a very arguable point.

I wanted to talk to you about something that is getting well outside our scope but unfortunately I think is relevant. I recently read an article in the *Canberra Times* headlined "How your religion changes your views on the right to die". I assume that you have seen probably not only this article but the more detailed statistics behind it.

I have only seen the *Canberra Times*. My question is basically: how representative is the ACL of the views of, firstly, Christians and then, if you have a view, Australians as a whole?

Mr Iles: That might be a good question for me to take. ACL represents our 125,000-odd supporters, people who sign up to us and believe in our platform. In terms of how representative of the church we are, that is a difficult question to answer except that our supporters are overwhelmingly Christian and we have constructive relationships with the churches, with denominations across Catholic, Orthodox and Protestant traditions. We often work with the key leaders in nearly all of the denominations. I can only speak at that leadership level and from the make-up of our supporter base, and that is as it is.

In terms of whether or not somebody's religion is relevant to their contributions on issues of public policy, of course it is. We all bring our identities to the table, whether that is a faith identity or something else. Often views are marginalised because they are faith driven, and I do not think that is fair. I do not think it is fair to marginalise a person's view because of their faith-based identity. Our supporters, nearly 2,000 Canberrans in this case, are as valid a voice as anybody else.

Dr Taylor: If I can just add something, I accept your point about government policy needing to address suffering. I was only meaning to say in terms of causation, that the government has not caused the suffering. Obviously there need to be policies to address it, and we need to work out how that happens. I was addressing Ms Cheyne's comparison of what happens as a result of these policies. Mistaken deaths as a result of a euthanasia policy would be the result of government action rather than government inaction; therefore, the ethics behind that are slightly different. That was the only point I was trying to make.

MRS DUNNE: Could I just follow up? Sorry, Mrs Kikkert has not asked a question.

THE CHAIR: I do note the time.

MRS KIKKERT: That is okay. I will pass my question to Mrs Dunne.

MRS DUNNE: Thank you. I just wanted to follow up on a point that you made. It has just fallen completely out of my head. Sorry; I will put it on notice.

THE CHAIR: I do note the time.

MRS DUNNE: I am sorry. It has fallen completely out of my head.

THE CHAIR: Thank you both very much for appearing today before the committee. There will be some questions provided on notice. There will definitely be one from Mrs Dunne, but there will be others from the committee. In relation to questions that are provided on notice, the committee is asking for responses to be turned around within 14 days of receipt of the *Hansard*. When available, a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections.

VAN DER LINDEN, MS BRANKA, Spokesperson, HOPE
DOUMIT, MS MONICA, Spokesperson, HOPE

THE CHAIR: I welcome our witnesses. Can you please confirm for the record that you understand the privilege implications of the statement in front of you?

Ms van der Linden: Yes.

Ms Doumit: Yes, I do.

THE CHAIR: Do you have a brief opening statement?

Ms van der Linden: Yes, we do, thank you. We thank the committee for this opportunity to appear and expand further on the written material we have provided in our submission. We are an advocacy organisation who care deeply about this issue, and we have been a voice of the public policy debate for close to a decade. The debate about whether our society should take the very serious step of legalising euthanasia and/or assisted suicide is one of great consequence.

We know our society places great weight on achievement, independence, youth, ability, success, and health and, as such it often leaves the elderly and people with disabilities feeling they are a burden or that they have no place in such an achievement-oriented society. A proposal to legalise euthanasia or assisted suicide in the ACT will subtly but surely create an unfair burden on vulnerable people who would feel pressure or even a duty to take the option that would now be available that was not there before.

Without the option of legalised euthanasia there is a general acceptance that when people get old and sick we as a community and a society will care for them no matter how long it takes and we will do all we can to provide them with comfort and care. We have a shared understanding that the government will adequately resource health care to ensure that everyone has their medical and other needs met.

As one commentator has noted legalising assisted suicide shifts the burden of proof in our society—the burden suddenly falls on the elderly and vulnerable to justify why they are not availing themselves of the option once it is valid and legal, particularly if it is viewed as an unselfish way to avoid drain on family, friends and society and especially in situations where it is not known or clear how long an illness will play out.

Assisted suicide affects not only the individual concerned; policy decisions made on the basis of difficult individual circumstances, however heartbreaking, without considering the broader consequences run the risk of ignoring the implications for others. The role of government is to ensure that policies benefit society as a whole and, in particular, prioritise protections of its most vulnerable members. Australia’s proud tradition of providing universal health care is evidence that we as a nation take this responsibility very seriously.

Overwhelmingly the Australian public want the priority for government to be adequately resourcing not just palliative care but also finding cures. Independent research commissioned by HOPE during the lead-up to Victoria’s legalisation of assisted suicide found that 51 per cent of respondents wanted funding priority given to cures, 36 per cent wanted funding priority given to improving and expanding palliative care, and only 13 per cent wanted funding priority given to legalising assisted suicide. This indicates that preservation of life is of greater importance to 87 per cent of survey respondents over early termination of life via euthanasia assisted suicide.

Palliative care should be the priority because it is a model of health care that addresses an individual patient's needs and cares for them in a holistic way at the end stages of life. It sends the message to a suffering person that they are valued, that their needs are important and that the community wants to contribute to their care, comfort and support as they go through the stages of an illness. Indeed evidence suggests that the earlier the palliative care is introduced into a person's life the longer their life expectancy and the better the outcomes for them and their families. The proper funding and resourcing of education about palliative care should be a priority for the government, not assisted suicide.

Finally, in speaking about vulnerability we must also mention the risk of elder abuse. We know elder abuse is a problem that is growing and we are weary of those who claim that safeguards can be implemented that are watertight given our current inability to address the problems facing our elderly. The Australian Law Reform Commission's report on elder abuse has stated that many cases of elder abuse go unreported. It is an error that is fraught and would be further complicated and made more dangerous if assisted suicide was to be legalised. I look forward to your questions.

MRS DUNNE: Ms van der Linden, can you expand on what you see as the issues of vulnerability? You may or may not have heard evidence we heard last week from Mr Craig Wallace from Lives Worth Living. He was quite definite that Lives Worth Living did not represent the universal view of people with disability, but the views that he put forward were that people with a disability were vulnerable to forms of coercion because of the cost of their condition, for instance. Could you expand on that from HOPE's point of view?

Ms van der Linden: Certainly. At the moment in our society we have a presumption that we do not kill, we do not take life. If you find yourself in a circumstance where you are ill, incapacitated for some reason or have a disability, there is a presumption that society will take care of you, that your medical and care needs will be met. Once the option is brought in that says, "This is something that's possible. You can, if you want, take your life," it creates a really difficult dilemma for the person in that situation. The possibility was not there before, then suddenly it is a question for them, "Do I do the unselfish thing? Should I impose myself on my family or caregivers for the long term of my life possibly, or should I do the unselfish thing and request assisted suicide?" The very fact of it being a possibility creates that dilemma and pressure.

I do not think anybody would be tapping someone with a disability on the shoulder and saying, "Your life's not worth living," but that message is being sent, whether we like it or not, because we say it is a possibility for people who feel their dignity has been breached.

MRS DUNNE: I could contend that some people overtly say that disabled lives are not worth living really. Anecdotally people report to us on a regular basis that if they have a child with a disability they are confronted in social circumstances where they are often asked, “Why did you let that happen?” It seems almost inevitable that that will extrapolate to end of life situations where people will ask, “Well, why are you perpetuating that which is less valuable?” As you said, if our society is about achievement and outcomes and success and goals, then the modest life of someone with a life-limiting disease might not be considered significant enough to perpetuate.

Ms van der Linden: Exactly, and if we do not have that choice then we as a society need to find ways to look after those people and provide for their needs.

Ms Doumit: I take your point exactly. We see the stigma against disability from the earliest of screening of embryos for different diseases. We see how many babies with Down syndrome are aborted. The rates increase once you get a diagnosis. If that occurs at the beginning of life, it is something that trails through towards the end, absolutely. Your question, Mrs Dunne, goes to the heart of the society that we want to be in introducing euthanasia and/or assisted suicide. What we are saying is that not only may the person in the street look at you and suggest that your life might not be worth living but it is almost as if the government itself is endorsing that position. That is an extraordinary move to take and one that we should take cautiously.

MS CHEYNE: Thank you for appearing today. I just wanted to touch a little bit on both elder abuse and the impacts on medical practitioners. Did you draw on a statistic from the Oregon annual report that around 50 per cent of people who access assisted dying do so because they feel like they are a burden?

Ms Doumit: We did, yes.

MS CHEYNE: I just want to clarify for the record—I think I am looking at the same year of the annual report and the table—that the people were able to submit a number of reasons for accessing it, which were not mutually exclusive. We do have “burden on family, friends/caregivers”—that was about 48 per cent in 2016. Equally, higher than that, is “losing autonomy”, which is around 90 per cent; “less able to engage in activities making life enjoyable”, 90 per cent; “loss of dignity”, 65 per cent; and “losing control of bodily functions” and “inadequate pain control”, about 36 and 35 per cent.

We have heard from elderly people and also in our submissions—I think that we have also seen it with the recent Dr Goodall case—that they have spent their lives contributing to society and feel that they deserve to be able to take their leave from this world peacefully and at a time of their choosing when they feel that they have no more to give or no more to contribute. If safeguards can be in place to protect against elder abuse, how can we really legitimately justify letting elderly people who do want to die wait until they are unbearably suffering or go through that to die?

Ms Doumit: Sorry, can I just clarify: is your question asking why would we not expand this regime, if it were to be introduced, from terminal illness to a number of the other categories like essentially just being tired of life, because that is—

MS CHEYNE: I certainly would not say “just tired of life”. I think “tired of life” is wrapped in a range of other things. But if an elderly person is dying from a terminal illness and they know that it is highly likely going to be painful or they are already starting to suffer from extreme pain, why should they not be able to access that if there are the appropriate safeguards in place?

Ms Doumit: I think your question almost speaks to why that is a risk. You mention the Dr Goodall case. He was not in pain nor was he dying of any terminal illness, but the overwhelming support for him to take that action existed simply because of his age. You point to statistics and, quite rightly, you say that a loss of autonomy, loss of dignity, control of bodily functions are all greater concerns than pain. It almost seems like we usher in a regime of euthanasia and assisted suicide pointing to cases where pain is the main concern.

What we are seeing from overseas and in anecdotal examples is that pain actually is not the major concern. The suffering that we are seeking to address is largely existential rather than anything else. To address that type of suffering by terminating a person’s life rather than having a community that supports those people—supports elderly and sick people in their journey—is not the way that we want to go. I do not think that is the makings of a good society.

MS CHEYNE: Just quickly, if I may: you also raised the issue that voluntary assisted dying can have a negative impact on medical practitioners. What if there was the option for a medical practitioner to conscientiously object?

Ms Doumit: Yes, absolutely, and we do see that in other countries.

Ms van der Linden: Yes.

Ms Doumit: I point to Oregon again. Because of the number of medical practitioners that are conscientiously objecting, we see the development of almost specialist doctors that deal simply in death. The same report that we were just referring to shows us that the median time a doctor who authorises the death treats a patient is 10 weeks.

From that, we see that you are not having somebody necessarily with an existing relationship with this patient; they are specially sought out just to authorise the death. Those statistics also tell us that the median time in days between the request being made and the person dying is 52 days. Seven—close to eight weeks—of those 10 weeks is taken up; the drug is already prescribed.

What we are seeing in Oregon is a person going to a doctor and within two to three weeks being given their lethal dose. There are doctors who conscientiously object. On the other side, we see the development of doctors who are not actually treating the patients. They are not investing in them; they are simply engaging in that box-ticking exercise. When you talk about the effect on doctors you are talking about not only the ones that want to conscientiously object but also the creation of really a specialist industry of Dr Deaths. That too is quite scary.

MS LE COUTEUR: You talked quite a lot about pressure, particularly on elderly people, but equally it could be on disabled people to choose voluntary assisted dying to reduce their being a burden on their family. I totally see that this is an issue. I am looking particularly at the Victorian legislation because it is the only one that is currently, sort of almost, on offer in Australia. A lot of safeguards were put into that. Some people have argued that there are so many safeguards that it would become somewhat useless.

Do you think there are sufficient safeguards in the Victorian legislation—that the amount of abuse would be very low—bearing in mind, as you have said, there clearly is already elder abuse? While this is a more terminal issue, it is not a new issue in any shape or form.

Ms Doumit: Sure, thank you. We hear a lot about the safeguards in Victoria. But in assessing the decision-making capacity of an eligible patient in Victoria, the only requirement is that they understand the information about assisted dying: that they are able to retain it, to weigh it up, and then to communicate their preference. There is no requirement to assess somebody's decision-making ability to see whether or not any of those outside pressures, including elder abuse, are part of that.

Interestingly, there is an option there to refer to the Victorian Administrative Tribunal to review a decision. But the people who are able to bring that review are limited. I guess, to my mind, if you have a person who is suffering from elder abuse and an interested neighbour—the New South Wales report into elder abuse tells us that the most likely people to be perpetrators of elder abuse are adult children—who can see what is going on and that there is some pressure being placed on mum or dad, they would struggle to present their case before the review board.

First, they would have to prove that they had an interest in that person. Then, the only grounds on which they would be able to challenge that decision relates to the residency of that person in Victoria or their decision-making capability. You actually cannot bring a case to the review board that brings in issues of elder abuse unless you can somehow prove that that elder abuse reduces their capacity to understand or retain the information. So I think that, even if you were able to pick up elder abuse and identify it, you would have a very difficult time in protecting that person under the Victorian legislation. I would be open to hearing other opinions on that. But from my read of the legislation, it does not protect against elder abuse.

Ms van der Linden: There are some analogies with domestic violence. As Monica said, the Australian Law Reform Commission report and the New South Wales parliamentary one state that most abuse is perpetrated by a relative, so either an adult child, a spouse or a partner of the elderly person and someone on whom they are dependent.

If you have a situation where there has been elder abuse over a long period of time, the person gets worn down. By the end, when they are getting the message, "Really, you should end it" they will go and just do it. There is nobody there scrutinising what has gone on before. I think that is a dangerous situation.

THE CHAIR: As with domestic violence, there can be cases where a little bit of hope somewhere can make the person much stronger and they can rally against those abusing.

Ms Doumit: Exactly. Yes, indeed.

MRS DUNNE: How would we inculcate hope in the circumstance of elderly people perhaps being pressured by a partner or their offspring to put an end to it so they can get the house? How do you inculcate hope in that circumstance?

Ms Doumit: I think by having real end of life choices available. If we go back to the Victorian example we see that at the time of legalisation, and I think probably still, they had the lowest per capita availability of palliative care specialists to the population. Report after report tells us that the palliative care situation in Australia is straining for resources. I think it is something like one specialist per 750 deaths or something like that. I can get those stats for you.

I think that you inculcate hope by giving people some control. The reason that people are so attracted to assisted suicide and euthanasia is because they feel that that is the way that they can control their death, that they can have control over this really uncertain time. But there are so many other ways, particularly a good and proper investment in palliative care, which would give them that same control and then that hope. But we just have to want to do it. We have to want to invest in that and inculcate hope in that way.

MS LE COUTEUR: I think the question probably is more this: how do we stop elder abuse? You have talked, both in your submission and in your opening statements, about how there is an expectation, obligation for care of elderly people. But there are certainly some elderly people and some disabled people who, whatever the expectations might be, are not being cared for. How do we change that? It is a big question.

Ms van der Linden: It is a big question; yes, it is. And it will grow as our population ages.

Ms Doumit: We do not envy your job, I have to say.

THE CHAIR: Thank you very much for coming in and talking with the committee. It is very much appreciated. When available, a proof transcript will be forwarded to witnesses to provide an opportunity to check the transcript and suggest any corrections, should they be required. I note, Ms Doumit, that you offered to provide some of those statistics on notice. That would be wonderful. Generally, the committee is requesting that all questions taken on notice be provided to the committee within 14 days of receipt of the proof *Hansard*. Again, thank you both for appearing today.

COLE, ASSOCIATE PROFESSOR ANDREW, Chief Medical Officer, HammondCare

THE CHAIR: I would like to welcome Associate Professor Cole from HammondCare to our hearings.

MRS DUNNE: Can I put on the record that I worked for Hammondville in my undergraduate days and in my university holidays, in another millennium.

THE CHAIR: I suppose I should put on the record that I was the main departmental officer that managed all commonwealth funding to HammondCare for the Department of Health and Ageing, but that was quite some time ago. Could you confirm for the record that you understand the privilege implications of the statement that is in front of you, please?

Prof Cole: Yes, I understand that, thank you.

THE CHAIR: Before we get started, would you like to make a brief opening statement to the committee?

Prof Cole: Please, if I may. Madam Chair and honourable members of this select committee, I thank you for the opportunity to appear before you today. Before commencing my remarks, may I first acknowledge the traditional custodians of the land we are meeting on, the Ngunnawal people. I wish to acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region. I would also like to acknowledge and express respect for their elders, past and present, and extend that respect to any other Aboriginal and Torres Strait Islander people who may be present today.

HammondCare is an independent Christian charity that provides community aged and palliative in-home care and support services. More specifically, HammondCare also provides and coordinates nationwide dementia behaviour management advice and rapid response services, into situations where people living with dementia experience severely problematic behaviours, through Dementia Support Australia. HammondCare also provides aged residential care and subacute hospital services.

In the ACT we are specifically active in providing a rapidly expanding program of home care packages and commonwealth home support for flexible in-home respite care for scores of elderly people living in the community.

I have practised as a specialist rehabilitation medicine physician since 1985, working in palliative and rehabilitation care settings in East Asia and Australia. And I continue in clinical work with frail older people and stroke and cancer survivors after serious illness, aiming to return them to live independently at home, where possible, with family and community support. I am Deputy Chair of the Royal Australasian College of Physicians Working Party on Euthanasia and Physician Assisted Dying, although I note that that working party has not yet reached a final decision.

Honourable members of this committee, you will have read our earlier detailed HammondCare written submission to this inquiry. So I shall focus my remarks in a couple of areas for special emphasis, if I may. These areas are: first, the complexity of end of life care and misunderstandings in the public discussion including conflating pain and suffering; second, people's perception of being a burden to those around them and its relationship to dignity and respect; third, the difficulties of determining competence in decision-making in people with cognitive and memory problems; fourth, the effect of suicide upon families, friends and healthcare workers and the relationship of this to difficulties in implementing legislative change; fifth, the lack of general availability of palliative care services to all Australians, with inequities in service distribution and funding denying people freedom of choice about when and where they would like to receive end of life care; and finally, the importance of frank and transparent end of life care discussions well before people reach that stage in their lives.

Care at the end of life is often difficult and complex. There is significant community misunderstanding about its role and effectiveness. Much public discussion about care at the end of life is framed in terms of pain and suffering as if these two matters are usually directly linked or always occur together or even that they will necessarily be present at the end of life, which is not the case.

Like other physical symptoms, most pain can be properly and effectively controlled with the correct choice of medications and routes for administering these, depending upon each person's situation, taken together with appropriate physical therapies and psychological support. Suffering is a more complex and highly individual experience with existential and psychological routes. Recent work has shown that suffering, as internally perceived by the person involved, often varies in its nature and intensity from day to day. Suffering needs appropriate counselling and support to address that problem. But for many people who receive good palliative care, suffering can also be effectively addressed and managed.

Palliative care is about managing all a person's needs at the end of life as and when they arise in a way that neither hastens nor prolongs the natural processes of dying that are occurring. In fact, many people actually express fear of anticipated pain and suffering rather than that which actually occurs when a person receives proper palliative care and support where these issues are addressed.

A greater problem that we encounter in reality, however, is when people late in life express that they feel they are a burden to the family, friends and carers, which implies that they feel a personal sense of reduced value to those around them. If we understand dignity as being the state or quality of being worthy of honour or respect, we know that dignity is in evidence when others are given the honour and respect that they are due. A person who feels they are a burden may often be feeling they are not being given appropriate human dignity by those around them. By meeting all the identified care needs of a person nearing the end of their lives, a palliative care approach gives each person the honour and respect that human personal dignity deserves.

In the setting where a person feels they are a burden and knowing that the reported incidence of some form of adverse social pressure or frank abuse in any given year affects around one in 10 older people, providing sufficient safeguards against external pressure or manipulation seems almost impossible. Nobody can be sure that conversations held behind closed doors are completely appropriate, especially in the setting of medical, personal care and nursing home costs and the residual quantum of value of a person's home or their other assets that may not remain to be passed on to the next generation.

Further, specialists who work with older people with cognitive and memory problems state that determination and mental competence for consent is not easy. This is true for really simple medical procedures, let alone determining competence for consent when a person might be asking for medical assistance in suicide. Determination of competence for decision-making in complex care or complex financial settings does require specialist advice and certification.

Turning now to the effects of suicide upon a person's family and a community, we know these effects are immense and long lasting and are often the cause of painful division in families after the event, let alone prior to a planned suicide. Further, there is emerging evidence, from jurisdictions where the law permits this, that assisting in suicide of patients has very important significance upon the health professionals, especially the doctors and also the nurses involved, many of whom say they cannot cope with being involved again in this way with patients in future.

In Canada many doctors are now asking for their names to be removed from the register of practitioners who are comfortable with assisting individual patients in this way. Over time in places like Oregon a small minority of doctors are providing support for the majority of assisted suicides, which is a long way from the originally intended model with involvement of family doctors who had long-term relationships with the individual person requesting help in ending their lives.

In Washington DC an individual, who incidentally was instrumental in the law reform in that district, wishing to request assistance with suicide, finds themselves in a setting where only a couple of doctors in the entire jurisdiction have registered themselves to assist with this, in compliance with legislation, more than a year after its introduction.

Like the WHO we advocate that only a fully informed and holistic palliative care approach in conjunction with excellent aged care for older people and excellent rehabilitation care for younger people with significant disability can hope to address properly the full spectrum of people's needs and care at the end of their lives. This spectrum includes each person's physical needs, control of their pain, nausea, breathlessness, other symptoms as they arise; their psychological needs; the needs of their social network of family, friends and those who provide care for them; and their existential—one might say, their spiritual—needs. Where is meaning in my present circumstances? What has my life been worth? What is my life still worth to the people around me?

At this point in time even the most basic level of palliative care is not available equally to all Australians, denying people their preferred choice of where and when they would like to receive care at the end of their lives. The bulk of holistic palliative care services is provided to people linked with the hospital system and mostly with cancer diagnoses. A majority of other people, especially those with the end-stage problems of ageing, have minimal access to holistic palliative care at the end of their lives, especially if they are living in community or aged-care settings and mainly cared for by GPs.

There is also a serious imbalance between palliative care service availability in metropolitan and rural and remote areas. This will only be addressed by substantial change in how palliative care in the community is funded, both in general practice settings and in community or nursing home care. Change is also needed in how professional students and practitioners are educated in formal settings, and good curricula do exist for this, and how non-professional home care and nursing care assistants are trained on the job—all this in both urban and regional and rural settings with cultural sensitivity for people under their care.

Finally, we believe that everyone needs to have the opportunity to think and discuss how they would like to be cared for at the end of their lives, long before they ever reach that point. This is in much the same way as everyone needs to make a will and provide for substitute decision-makers well before the needs for any of those matters arise.

To summarise, we advocate that the most appropriate approach is to provide palliative care at the end of life that meets people's needs in a holistic way and treats everyone with individual dignity while ever they are alive. This care should neither hasten nor prolong the natural process of dying. This care should then provide good support after a person's death for all members of their family, friends and healthcare workers who have provided the end of life care for them.

MS CHEYNE: You were talking about what is happening in Canada and the distress for doctors, and that some have been removing themselves from that registry. Can you tell us where that information has come from?

Prof Cole: We came across this in the context of the college of physicians working party. It is coming from the press, and it is coming from reputable publications where it is being reported. I believe that was from the Toronto *Globe and Mail*.

The other matter I alluded to, Ms Klein in Washington DC, was the subject of a detailed report. That was Ms Klein herself saying, "I cannot find the service that I have advocated for being available." That was in the *Washington Post*, which I do not think I need a movie starring Meryl Streep to tell me is a good paper with good resources. That was published on 10 April. She found that only two doctors in Washington DC were registered under the legislation 12 months after it had been brought into effect.

I mention those because reforming legislation and responding to society is one matter, but actually introducing legislation that covers all the ground and making it operate is another matter entirely. One of the difficulties is that I think there is always an assumption that doctors are the people to do it. I did train a number of years ago, and I did train in a very biological era, but we were taught about medications that helped people and we were warned about the side-effects of dangerous doses. I do not know of a doctor in the land who has been trained specifically in what constitutes a poisonous dose reliably in every case, for example. So there is that issue.

MS CHEYNE: I have just been reading, in the *Globe and Mail* from last year, about some of those reasons that have been reported. Yes, you are right; there are quite a few articles about doctors taking themselves off the registry, including that some doctors have raised concerns about the distress. But interestingly—and I think this goes a bit to what you were talking about with palliative care and providing that in rural and remote areas, and I am very happy to share these articles with you—some Canadian doctors are taking themselves off the registry because the fees for assisted dying are so low that it makes it not worthwhile for them to travel to rural and remote areas. The *Globe and Mail* reported this week that some providers in British Columbia are bowing out because they say new fees for the service are so low that they cannot afford to continue accepting referrals, especially in cases that require travel. In Nova Scotia, about half the claims filed so far for assisted death are stuck in processing.

Prof Cole: With respect, “it is said that some doctors are” is hearsay. We were looking at articles where people have written to say, “I am uncomfortable in this situation.” I hear what you are saying—

MS CHEYNE: It is the same newspaper.

Prof Cole: I am very concerned about the ethics of somebody who does not do something because it does not pay enough. That is not the way we practise within HammondCare, and it is not the way we practise within palliative care and our disciplines.

MS CHEYNE: No, indeed. That is not the only reason that people are providing. It seems that one of the major concerns is about the coordination of the service, and also about the paperwork and bureaucracy. Another reason given is the scrutiny and scorn from colleagues, the pressure around that—and confusion, even, over who exactly qualifies. I think that suggests there were perhaps issues with the Canadian legislation.

I wanted to talk a little about the pressure of the relationship between a practitioner and their patient and also the practitioner and their colleagues. Would you have concerns about how people would feel, and the psychological impact on them, if they were participating in the scheme but perhaps were surrounded by people who were not?

Prof Cole: The difficulty is that in one sense it is hypothetical, because it is not the case in Australia and therefore I do not have experience of that with professional colleagues.

I think that the distress that I hear people talking about is actually related to distress around caring, supporting and being involved with a person in the situation of suicide. The distress I see within my colleague group is around older people who often have mental health issues and who are struggling with making sense of what is happening in their lives. In this day and age in Australia, we still have suicide prevention programs that run at all ages. Despite a lot of work from a lot of people, still people choose that approach for themselves.

The distress that that causes to the people in the families around them and the medical staff looking after them is considerable. I have seen it in experienced colleagues, specialist colleagues, who have had particularly difficult circumstances to deal with. It has required that they take a couple of months of leave to put their brains back in gear and sort out and process the experience. And it is often not just one; it is often two or three over time. I think that the effect of offering this potential for people on the healthcare workers and the community care workers that are involved in the care of these people really should not be underestimated. It is a real issue.

As previous people said, those of us on this side of the table do not envy you in your task of working through this situation. It is very difficult. There are social pressures on the one hand, and people try to produce legislation they think works, but then the effect of that legislation in real practice on people is very difficult. Even in a situation now where we have not got the legislation in place and things are happening, it is very difficult.

MS CHEYNE: Yes, and I think that is probably my point. The act of assisting someone to die is potentially very distressing. But equally, I am sure there are many practitioners and carers at the moment who are dealing with patients who have been suffering interminably and then do choose to take their own lives, often without the support mechanisms of their family and friends, because they do not want to further implicate them. That has its own flow-on effects.

Prof Cole: I guess the question we have is: if we accord dignity to the people we are working with and caring for, we need to be addressing their needs, talking with them and listening to them. That takes a lot of time. Suffering, because it has not been terribly well studied or described until quite recent years, is this thing that people feel they cannot deal with.

There has actually been quite a bit of research, including by an individual connected with our organisation, looking at suffering: the experience of suffering and the support and management of suffering. It is like a lot of things in health care: if you can describe and then understand—it is a bit medical, but I would use the word “diagnose”—you can start to help a person through those problems.

In the same way, if you think pain is just pain—if you do not sit down and think, “Well, what kind of pain is it? What is affected? What medication is going to help that? What physio is going to help that? What psychology is going to help the ability to live with that pain or deal with that pain?”—I do not think that we are addressing a person with dignity if we are not addressing their needs.

If a person says they are suffering, I think it is incumbent on carers around them to listen, to ask, to find out what is happening. One of the difficulties with ageing in our society and families being spread over distances is that old people often do not have close networks, often do not have people very close to talk with, often are not connecting. In that situation of loneliness, all sorts of things come along afterwards or are not seen.

I was listening with interest to the previous pair of ladies presenting, and I think it is true that there are people who are lonely, not valued, not given dignity, but could and should be supported and cared for and have those needs met as a priority.

MS LE COUTEUR: You, to an extent, and in fact all the speakers this morning, have touched upon elder abuse and people feeling that they are a burden on their family, society or whatever. Clearly, that is a real issue. Can you think of any way that we can safeguard that? If there was voluntary assisted dying, how could we put in safeguards about that, given, as we know, that the people involved in elder abuse may also be the people closest to the elderly person?

Prof Cole: Yes, absolutely. When I was a third-year medical student, I was taught never to say never. I am of the view that I do not think it is possible to put in absolutely watertight safeguards against the possibility of abuse, simply because I cannot know what goes on behind closed doors and I cannot know exactly what goes on in other people's minds. There are times that I have enough difficulty working out what is going on in my own mind at times.

It is a real issue. The nature of abuse is that it is well hidden. We kind of know it is there, and we get a terrible shock when people start to uncover it. Think about the awful things that Peter McClellan's royal commission uncovered in his situation and the extent of what was there. People knew it was there, but nobody realised the extent of that abuse in that situation.

The pointers are that elder abuse is far more common than we like to think or believe. Because I cannot imagine me abusing my mum, I find it very hard, although I understand why it happens, to accept that it is as common as the research is telling us it is: one in 10 every year, from a very large, multicentre trial, from previous evidence.

MRS KIKKERT: My question is about the burden that many elders feel at the end of their life, how they are a burden to their family members and also to their friends. How can we improve that as a community? How can we support elderly members not to feel that way but to feel the support not only of family members but of friends and the community, rallying for them to strengthen them? How can we move forward to that?

Prof Cole: Ultimately, the answer lies in us being a community that values people, to want to make contact and keep socially involved and active with people around us who we realise do not have necessarily family or close social support. There are people like that living all around us if we have eyes to see it.

Even people who have achieved at the most incredible level in their lives—senior politicians, senior people who have done amazing things in their professional practice and in community support, who have been awarded and honoured, and I have had the privilege of caring for people like that in my practice in the last five or 10 years—get very lonely.

It is the existential question: "Now I am old, was what I have done worth it? What is my worth to people around me now?" The first thing is to be aware of people; the second thing is to listen when people say things that indicate they are feeling unvalued; the third thing is to keep listening and talking, and be a friend to them. That is something that everybody and anybody can do with minimal training, but we are so damn busy in life that we do not do it.

THE ACTING CHAIR (Mrs Dunne): As we are here for most of the day, occasionally members have to step out to do other things, as the chair has just done. I will take over as acting chair. I want to thank HammondCare for submitting. I was very keen to see an organisation like HammondCare before the committee because you are a stand-out by virtue of the fact that you are probably one of the only aged-care organisations that has submitted to this committee. What we are hearing a lot—

Prof Cole: Goodness!

MS LE COUTEUR: Yes, very surprising.

THE ACTING CHAIR: Yes, it is very surprising. What we are hearing a lot is that a lot of people die in aged care or that their final home is in aged care.

Prof Cole: Yes.

THE ACTING CHAIR: Anecdotally, we are hearing that a lot of aged-care facilities do not cope with end of life issues. The Productivity Commission report, which came down on human services in April, goes into some detail on that. HammondCare is in the panoply of the good achievers.

Prof Cole: Thank you.

THE ACTING CHAIR: From my understanding and my reading of things—not just the fact that I worked with you many years ago in a previous millennium—I ask this question: what is it about the service that HammondCare provides? What can it teach other aged-care providers about end of life care in an aged-care setting?

Prof Cole: If you have ever met our CEO, Stephen Judd, you will know that he is exceedingly keen on our view that we treat every single person we care for as a worthwhile individual person with dignity. It stems from our original founders' Christian view that all humans have something particular of the likeness of God in them, whatever that means.

But it means that whether a person is young or old or frail or demented or disabled or whatever, they are recognisably human and they need to be accorded the respect and dignity that being a human gives. That then leaves us to say, "Well, I am human. If I was that person, how would I like to be treated? How would I like to live?" That leads us to think about practical things. If we are building a nursing home, would I like to live here? Would I like to be in a cottage-type situation or would I like to be in something that looks like a hospital ward?

If we are providing community care, would I like to know that the carer is going to come when they say they are going to come? Would I like to know that the person is skilled and listens to me and is available if I get into strife? It really is the outworking—it is not just Christian; every religion has this—of doing to others what you would have them do to you. If you are an honourable and virtuous person, that leads to a particular kind of care and a particular kind of way of doing things.

It has led us to work hard, as you probably know, particularly in the area of dementia where there are significant cognitive issues. People say things like, “It is not mum anymore because she has got dementia.” But it is mum. It is just that mum has grown and changed—

THE ACTING CHAIR: It is a different manifestation.

Prof Cole: Yes. So that has led us to do research to find out how it is that we can help that family get some access to some of the old mum that is still there, buried inside in the outer appearance. We may do that through music and singing, through art, through pet dogs or cats being allowed in nursing homes—not in the same nursing cottage—or by providing an environment that allows people to walk if their dementia means that they are restless and anxious and they need to walk. We provide them with a safe environment where they can walk as much as they like so they can expel their anxiety without having to use medications to bomb them out. I do not know that that is a very precise answer but—

THE ACTING CHAIR: That is at the philosophical level.

Prof Cole: Yes.

THE ACTING CHAIR: I would like to drill down to the practical level. What we are hearing is that overnight in nursing homes there may not be very many staff.

Prof Cole: Yes.

THE ACTING CHAIR: There may not be registered nurses; there may not be access to the drugs cupboard, which means that often if there is a crisis, the patient is—

Prof Cole: Carted off to hospital in an ambulance, yes.

THE ACTING CHAIR: sent off to hospital in an ambulance. How do you address those issues so as to minimise the necessity for emergency transfer to the hospital in the middle of the night? Also, what we are hearing is that there is a reluctance for families to send their parent or significant elder back to a residential care environment if they are close to death because they do not see that they are getting the right level of service there.

Prof Cole: Yes. The first thing is that we do ensure—obviously, the funding of the aged-care system is such that the majority of staff are not university graduate registered nurses. They are enrolled nurses or personal care assistants who are essentially TAFE trained. One of the critical things is that the numbers are adequate. There should be a certain minimum number of people caring for older people in relation to the number of people under care. That, I think, is very clear. It should be mandated. My view is that a nursing care facility should have a registered nurse on duty 24/7—or very closely available 24/7. We do have that in HammondCare.

THE ACTING CHAIR: Actually on duty or on call?

Prof Cole: On duty, on site. Because of the size of the nursing home or if it is in the country somewhere and it is not economic to do that, they should have somebody who is on call and able to get there very quickly.

THE ACTING CHAIR: What we hear is that there is a reluctance to call out that person because then they are on overtime or something like that; there is a cost involved.

Prof Cole: I come back to the question of dignity. What is a person worth?

THE ACTING CHAIR: For Hansard, Professor Cole was shaking his head.

Prof Cole: For the record. The other thing is that we are developing networks of general practitioners in relation to our nursing care facilities that have a good number of outpatients under their care. At Hammondville we now have a university general practice and a dental care service on site so that we have a number of practitioners that come and do sessions with us. They see the walking wounded in the clinic and they walk across the road and see those that cannot walk in their beds.

One of the things that it is really important to realise with older people with acute illness is that it does not often happen bang on the day that the emergency happens. It is normally brewing over a couple of days previously. With good general practice care prior and well-trained GPs you know what to look for. They can often get in and intervene in an appropriate way.

If it is an infection that is brewing, they can treat it with antibiotics. If it is, say, some sort of cardiac event that is obviously going to be the end of life event, they can diagnose that and then they can start to give the person the pain relief that they need for the pain, anything they need for breathlessness and try to get them into a situation where they are getting palliative care in the nursing home setting.

At Hammondville we do actually have a part of the nursing home that is a palliative unit in itself. We have GPs who know what they are doing and we have a visiting palliative care specialist that comes for a couple of hours once a week to advise and support those GPs. The difficulty at the moment is that geriatricians do not often go outside hospitals. Palliative care specialists are much better at going into the community but there just are not enough of them to deal with nursing homes. So what they tend to do is provide a nurse consultant to go and help the nurses on the ground.

But my mum, 96½, is in a nursing home that is not run by HammondCare, because we do not have one in her part of town. I twisted the CEO’s arm but unfortunately it is one of those things. I see firsthand what happens there. It is another group. They are very well-meaning people but they do not do things the Hammond way. I am in and out helping them care for my mum in the way that I think should be done. I am actually informally doing a fair bit of teaching and support in that process. I am seeing the reality of that situation.

I think a lot of people are just overwhelmed. The population in nursing homes has changed in the last five years. People used to be in nursing homes for much longer periods of time than they are now. The average length of stay, I think, now is dropping down to around 15 to 18 months. You do not have people that are living in nursing homes for 10 years after a stroke because they could not go home. It is much more about people with multiple organ failure, multiple medical problems, dementia, and they really are in the celestial waiting room.

THE ACTING CHAIR: I hate to do this, but I am going to drill down even more into the practicalities.

Prof Cole: Sure.

THE ACTING CHAIR: Is HammondCare able to quantify a per capita cost for the sorts of end of life services that you provide? Can you quantify that?

Prof Cole: I reckon that if somebody were formally to ask our CEO, I am sure he could do it, yes.

THE ACTING CHAIR: We might put that on notice.

MRS KIKKERT: Yes, that would be good.

THE ACTING CHAIR: I am looking at the Productivity Commission report and it talks about what they see as the cost of palliative care in the community as being something in the realm of $10,000 per person per year. It builds up to a large number but not a horrifically large amount. It seems that a lot of what we are hearing is that we are not good at palliative care. There are good, standout places that provide palliative care; but it tends to be quite concentrated.

Prof Cole: Beacons in a lot of darkness.

THE ACTING CHAIR: Yes, thank you for that analogy. The ACT has a palliative care system which is highly regarded but there are a lot of people who would benefit from availing themselves of that service who do not and who die in hospitals, not in a palliative care setting but in a general ward setting, which seems to be entirely inappropriate. We are hearing—to some extent this is not much better than anecdotally—that a lot of aged-care providers are not stepping up to the mark in the way you have described here. I am saying that because maybe somebody is listening and they want to make a submission about how they are doing it really well in Canberra, because we are not hearing it.

So you are telling us that if we write to your CEO at HammondCare he should be able to assist us with quantifying the cost?

Prof Cole: Should be able to provide some information, yes.

THE ACTING CHAIR: I am mindful of the time.

Prof Cole: Can I just say one thing?

THE ACTING CHAIR: Yes.

Prof Cole: Thirteen years ago my father suffered a devastating stroke. My brother and I had spoken to him beforehand about what he wanted done at the end of life. He had a stroke that was very like a friend of his who survived, and Dad had said to us, "If that ever happens to me, don't let them keep me alive." He went to a very large royal teaching hospital in Sydney, and after two days obviously he was not going to get better and they were saying, "Well, he can stay here." I asked, "Why aren't you going to refer him to palliative care?" Admittedly, this was 13 years ago, but they had not thought about it.

I had to struggle to get him into a palliative care situation. And I think it is still the case with a number of people that are dying in those situations, as you say, in a teaching hospital. The difference in the palliative care situation was just incredible. He partially regained consciousness five days after the stroke and on the morning he died, and that is not uncommon in that sort of situation; people have those lucid intervals. Being in a situation that was not noisy, was not bustling, had nurses who were caring for him well and that had pastoral support of the family sitting around the bed—because it is a long process in some situations—meant the difference between that and an acute care hospital was incredible. And the dollar cost per diem is about half of the acute hospital.

THE ACTING CHAIR: One of the messages we are hearing is that doctors do not know when to refer people to palliative care. It also seems to me that people acquaint palliative care with cancer, so perhaps oncologists are good at it but specialist physicians may not be quite so good at it.

Prof Cole: And the services that are there are largely occupied with cancer patients. So it is very difficult for people with end-stage renal disease, cardiac disease, let alone dementia, to find places where they can be referred for palliative care.

THE ACTING CHAIR: In relation to the way HammondCare operates, do all dementia patients in your care eventually find their way into a residential nursing home type context, or do some of them live out their days in cottages?

Prof Cole: We try and support as many at home as we can, and that is what our home-care services are about. When the family find they cannot cope or there is no carer available, that is when they come into residential care, and the residential care is provided at the level of the person's need. The "cottage" refers to the environment, not the level of care that is provided in that environment, if you know what I mean.

Our new-build nursing homes are in clusters of eight or 12 beds in a cottage-like situation. You walk in the front door, there is a living room and there is a kitchen. We do not need to ring a bell to say lunch is on because you can smell the food cooking. If people want to help with cooking, they are allowed to do that. Then each person has a bedroom up a corridor close to that central area.

THE ACTING CHAIR: And pets if wanted.

Prof Cole: And pets if wanted, absolutely.

THE ACTING CHAIR: I will hand back over to the chair.

THE CHAIR: Thank you, Professor Cole, for spending some time with the committee today. When available, a proof transcript will be forwarded to you to provide you with an opportunity to suggest any corrections. The committee asks that all questions taken on notice be replied to within 14 days of the receipt of the proof transcript. We will suspend for a short morning tea break.

Hearing suspended from 11.06 to 11.17 am.

BIKSHANDI, DR BALAJI, Board Member, Australian Medical Association (ACT)
SOMERVILLE, MR PETER, Chief Executive Officer, Australian Medical Association (ACT)

THE CHAIR: Welcome to our next witnesses. Could you confirm for the record that you have understood and read the privilege implications of the statement in front of you?

Dr Bikshandi: Yes.

Mr Somerville: Yes, I have.

THE CHAIR: Thank you so much. Before we proceed with questions from the committee, would you like to make a brief opening statement?

Dr Bikshandi: I would. Thank you, everyone, for the opportunity to appear today and give the views of the AMA (ACT) on the important matter of end of life issues in the ACT. I would like to acknowledge the custodians of the land on which we meet today, the Ngunnawal people, and pay respects to their elders, past and present.

I am a board member of AMA (ACT) and appear in that capacity. I am also an intensive care physician with appointments at the Goulburn Base Hospital and as the clinical leader of the intensive care unit at the North West Regional Hospital in Burnie, Tasmania. I previously practised in the ACT at the John James Hospital; also in Queensland and New South Wales.

End of life issues are difficult. The community is concerned that we should treat them seriously and conscientiously. The medical profession is part of the community and cannot stand aside from that discussion that is going on. Indeed it needs to play a key part in it. Today we are appearing on behalf of the AMA (ACT) to give our views on these issues.

Firstly, I would like to repeat the primary position of AMA (ACT) in regard to the organisation’s view on voluntary assisted dying, which is that the AMA believes that doctors should not be involved in interventions that have, as a primary intention, the ending of a person’s life.

The submission we made did not touch on whether the medical profession is supportive of or opposes voluntary assisted dying. The focus is on whether the AMA believes that the medical profession should be involved in voluntary assisted dying.

Despite this, we recognise that the medical profession is part of a wider community, and should our civil society move to introduce a scheme of voluntary assisted dying, the medical profession would wish to be involved. Of course, with the Victorian model now being implemented, set to commence in mid-2019, there will be many things that can be learned from that experience should the ACT move to do a local scheme. Given the current federal legislative bar on such schemes in the ACT, we may yet have some time to wait should the ACT choose to introduce a scheme.

Finally, I would like to make mention of some additional information I have in regard to how patients may be assisted in exercising their preference in managing the end of their life. As an intensive care physician working in different jurisdictions, I am aware of the difficulties faced by patients and doctors in getting a clear idea of how we should proceed at the end of a patient’s life. We are happy to accept questions.

THE CHAIR: Thank you so much.

MS LE COUTEUR: There are lots of possible questions. One of the obvious ones is this. We have heard very differing evidence about palliative care. There are two things that I am interested in. One is the universal effectiveness of this or otherwise. We have heard some people say that there will always be a palliative care solution for whatever problem, whereas other people say that is not actually so. The other question is about the availability of palliative care regardless of whether it has some holes or not, just the availability of it for patients in Canberra. There seem to be significant issues with people who appear to be eligible for palliative care not being able to receive it in any timely fashion.

Dr Bikshandi: They are very good questions. In the two distinct questions that you have asked, one is about the efficacy of palliative care and whether that is universally a panacea for all these end of life solutions. The overwhelming majority of medical practitioners, including myself, would agree that it is not. There are certain situations where palliative care, by the definition of utilising drugs or medications to alleviate symptom control, may not be sufficient. There are specific examples.

In relation to the second question, regarding the availability of palliative care services, the previous position statements allude to the need for more funding in developing these services, which simply means that the demand is not met adequately.

MS LE COUTEUR: Would it be useful to have more services like Clare Holland or more nurses who can consult or get back into nursing homes and people’s homes? Where do you see the gaps that could be most usefully filled? It has been suggested to us also that Canberra Hospital should have a specific palliative care ward. I gather they do not at present.

Dr Bikshandi: That is a very good question, Caroline. I am an intensive care specialist. The accurate or near accurate answer can be provided by someone who is a palliative care physician, but I see deficiencies in palliative care even in hospital settings, within an acute care hospital itself. With regard to what would be a better choice, whether it be a community-based palliative care service or improving palliative care facilities, I think that would be better answered by someone with palliative care as a speciality. What do you think, Peter?

Mr Somerville: I think that is right. Unfortunately, our submission has not gone to that, and at this stage we have not actively sought information on the need, for instance, for in-home palliative care services and those sorts of things, which would be one of the areas that come up.

MS LE COUTEUR: You are obviously practising in a hospital; you are an intensive care specialist. Would it be useful, do you think, in the hospital environment, to have a specific ward for palliative care rather than have people at that stage of life mixed in everywhere in the hospital?

Dr Bikshandi: There are facilities which have specific palliative care wards, but the constraints of the current hospital systems mean that we tend to use any room that is available. Any place can be improvised to provide palliative care. It would be nice—it may be my personal opinion—to have an exclusive area within a hospital facility where palliative care patients can be looked after by a specialised group of nurses and doctors.

THE CHAIR: You stated that it would be nice to have an individual palliative care unit. This is just a question; I have no idea. I am trying to figure out how to ask this without being disrespectful of people; I apologise if it does not come out quite as well as I am hoping. Having not been very close to people that have been near death, is it the case that some people may enjoy the fact that they have company of others around them that are not necessarily family, that are not necessarily dying but may be unwell? Does that make a difference to the life outcome or to the care given to the feelings of the person who is dying?

Dr Bikshandi: As a general rule, in intensive care literature there is evidence to support that the care outcomes actually get better with the families present by the bedside, family or next of kin. In fact the visitation restrictions, the timings, are nowadays considered a bit unethical when it comes to intensive care. There are a lot of discussions. There are even some studies which say that such restrictions have an impact and negative perceptions from the patient’s side. That study is organic. There is growing evidence that there is definite improvement in outcomes if family or next of kin or friends are by the bedside. In the places I practise, we do not have tight visitation rights for patients that are that sick.

When it comes to patients who are end of life, generally there are two divergent thoughts that you will easily see among patients. One is when a group of family members would not want to see certain end of life situations; they would rather stay at home. I have come across them. The majority would want to be with a patient when they pass away or at their end of life. There is no easy answer to it, but I think the answer is an individualised circumstance, and the health system should be flexible in accommodating the requests of the family or next of kin in that aspect.

MRS KIKKERT: Your national president has said in the *Guardian* newspaper that there is a need to consider the possible negative impact of euthanasia and assisted suicide legislation on the rest of the health system. Would you care to expand on what those negative impacts might be?

Mr Somerville: I saw that, and to be honest I am not particularly aware of what the now former AMA president, Michael Gannon, meant by that precisely. We could attempt to find out from him and get back to the committee on that. I am not specifically aware of the detriments he had in mind.

MRS KIKKERT: Do you foresee any negative impact on society?

Mr Somerville: Of?

MRS KIKKERT: If euthanasia or assisted suicide is legalised?

Mr Somerville: I suppose we came here today to represent the views of the AMA insofar as that goes. That is a little outside our remit today.

MRS KIKKERT: Understood; thank you.

Dr Bikshandi: In my personal view, it is too early to tell what impacts, negative or positive, will arise from something that we have not even got yet. Maybe we should look at the countries that have ratified it and are doing it. We may have to look at the Victorian model and see what the impacts are. “We do not know yet” will be the right answer.

MRS DUNNE: What you are saying is that you do not know in Australia because we have not been there, but you have put together a statement in relation to end of life choices. Was it informed by experience in other jurisdictions overseas where there is euthanasia, voluntary assisted dying or whatever you would like to call it?

Mr Somerville: That position statement was developed through the federal AMA. I know they are aware and have taken into account some of those matters internationally, but it was really focused on the local situation in Australia and amongst the various jurisdictions.

THE CHAIR: In relation to advance care planning, I note that you have a position statement in regard to advance care planning and end of life choices. From an advance care planning perspective, we have heard from some witnesses, over the course of this inquiry in particular, that there are some medical practitioners that do not necessarily look at an advance care plan, do not necessarily understand or do not necessarily want to take it into account.

As members of the AMA—and this is more literally as members of the AMA—is there an education program that you have looked at? Are there ways in which we can have advance care planning discussed more with members of the community, discussed more between GPs and their patients, and discussed more across the board? I would be interested to hear your insights.

Dr Bikshandi: I would not be able to generalise on the view that medical practitioners do not see that, because from day-to-day practitioner experience, my own experience is that I do look for advance care directives. Unfortunately, you may not get them for every single patient. And even if you do, those statements are so heterogeneous.

There are two concepts in it. The advance care directive comprises advance care planning, and there is another component built into it clearly called care planning, which is what we would be interested in. My own personal experience is that that clinical care planning aspect is not very well standardised across jurisdictions. I am not sure who executes it. Is it a legal practitioner that does it or a general practitioner that does it? The clinical care planning aspect involves directions on interventions like cardio problems and resuscitations. Again the medical word is so complex; it is just compressions when the heart stops. That sort of split into small elements is not done with the patients. You come across very interesting statements like, “If it comes to that point, give me the needle.” There is that sort of thing.

It is very hard to implement what is asked for within an advance care directive, especially in the context of clinical care planning. There needs to be standardisation. Education from the medical practitioner perspective aside, I think there should be some standardisation in the clinical care planning area. What many hospitals do across jurisdictions nowadays is that we have what are called goals of care, especially with intensive care. A patient comes in and we set out the expectations of care. Is this a curative intent, is it going to be limited life support with intent, is it going to be a palliative care intent or is it going to be a comfort during dying process?

This advance care directive sometimes is not easily transposable into that document. The advance care directives, the wording of their views, may not be easily transposable. That is a big limitation that practitioners will face, including the absence of data on whether they are willing to donate their organs or not. Not always: some patients express that; some do not. There needs to be standardisation. That is what medical practitioners would agree.

THE CHAIR: We have heard from other doctors that have given evidence that it is very difficult as a general practitioner to find the time to sit down with a patient to go through all of the things you have just raised plus more. There were some comments about the fact that if it was part of the medical benefits scheme or a billing code within the schedule, it could encourage more GPs to have those longer and often complex conversations with patients. What would be your views around those things, noting that this is a local jurisdiction and we cannot necessarily influence those things? It is just an interesting concept.

Dr Bikshandi: There is a move by some medical practitioners to have an item number created for end of life discussions. It does consume a significant amount of time, and it is an individualised expectation-matching situation. They have to invest a lot in it. In my own experience, end of life discussions cannot be done during regular ward rounds because of the set time frame. So there may be validity in some medical practitioners’ view that there must be an itemised number for this, which obviously impacts on their clinical practice duration. I am not sure how they will do it, but there is definitely that.

Whether GPs can do all of these aspects that I mentioned, even if an item number is created, or whether they should have someone like an intensive care specialist look into it on a case-by-case basis where they have a discussion in the GP’s office as to whether this is all appropriate for this patient or not, I am not sure, but it is a discussion that has started.

THE CHAIR: We have heard from many witnesses that, in general, death is a difficult conversation to have between family members, let alone having it in a very clinical setting.

Dr Bikshandi: It certainly is. In any end of life discussion or discussion of limitations to the care framework, there is no one size that fits all; you have to take into account the expectations of the general world, the general community, and the individual expectations, which vary. It is a difficult conversation to have, but fortunately we see more and more of these conversations happening in the community, which is a positive step.

MRS DUNNE: It is also interesting to note that the Productivity Commission's inquiry into human services has recommended an item number.

THE CHAIR: It has, yes.

MRS DUNNE: Not necessarily for GPs, but they have recommended an item number. That is probably part of that conversation.

THE CHAIR: Mrs Dunne, do you have a substantive question?

MRS DUNNE: I want to dwell on the issue of palliative care and the AMA's experience of palliative care in the ACT—the extent to which it is available and the extent, perhaps, to which it is not available, particularly in residential aged care. I just want the AMA to comment, as far as it is able, through its members' experience, about where there are likely gaps. We know that there is not enough—the universal evidence is that there is not enough—but where would you see the gaps needing to be addressed, and do you have a view about the cost?

Dr Bikshandi: I think the best person to answer that would be a palliative care specialist who has an understanding of where the exact deficiencies are. From an intensive care point of view, I do find that community-based palliative care across various jurisdictions needs more boosting. Significant proportions of patients prefer dying at home. Community-based palliative care, with visiting nurses or visiting palliative care specialists, at the moment is a key area of deficiency. Even talking to other colleagues, that is one of the key areas.

The second area which I face is in hospital. I am not sure about the palliative care dedicated facilities and how much resource constrained they are; that would be better answered by someone in that speciality.

MS CHEYNE: Thank you for covering so much about communication, about death and those choices at the end of life. I think it is a really substantial part of our inquiry. Particularly in relation to voluntary assisted dying—I know you have touched on this but I would be grateful if you could just expand on it for the record—if it were to be legalised in the ACT, what safeguards would you like to see introduced, to protect the vulnerable and, equally, to look after, for lack of a better word, practitioners?

Mr Somerville: I know this must be a frustrating inquiry for everyone involved because of the current federal legislative bar in that aspect. But of course—

MS CHEYNE: Let us pretend that does not exist.

Mr Somerville: That is right. It is important. A very good reason for doing this inquiry is to gather community views in regard to it and to assist in dealing, hopefully, with that bar.

The fact is that we have thought about this. There is a model out there that was undertaken through a process which followed a parliamentary inquiry in Victoria. There will be a lot of learnings that come out of the implementation of that scheme in Victoria once it is fully underway in the middle of next year. We think that if the Legislative Assembly decides to move to a scheme of voluntary assisted dying in the ACT, an appropriate way to deal with it is at that point to likewise walk through a further expert inquiry into what that framework should look like.

Dr Bikshandi: From a medical practitioner's point of view, the key areas are about, first, identifying the group of patients that will benefit from it. As we spoke about earlier, palliative care is probably not the answer to every end of life situation. That group of patients has to be identified. Second, how are we going to implement it? Will it be through a specialised group of doctors who specialise in this area? Or could we use the analogy of, say, the brain death testing that we do for organ donation reasons? ANZICS, the Australian and New Zealand Intensive Care Society, has a published statement: two practitioners—one of them would be a fellow of the College of Intensive Care Medicine; the other one could be another practitioner—independently test and confirm. There are two ways to deal with it: everyone has this authority or only a specific group of doctors has it. That is the other area.

The third area is a very complex area to tread on. The things that can arise include asking what happens if the patient is not compos mentis. What if the surrogate decision-maker has to make such choices? What about the Mental Health Act and its implications for these decisions? Another complex area is: what about organ donations in this situation? There are a lot of complicated regions that, as Peter mentioned, may need intercollegiate discussions and expert reviews.

The main thing will be protecting the patient's best interests and the practitioner's best interests. And there is the question of how these will be audited and what other liabilities the persons that are involved will have to take. Those are the areas that need expert input, perhaps an intercollegiate discussion between different specialist colleges in these areas.

Mr Somerville: Returning to the current position statement, we stated earlier what the primary position of the AMA is in regard to voluntary assisted dying. But there is another component in that, clause 3.4 of the position statement on euthanasia and physician-assisted suicide, basically to the effect that if governments decide that laws should be changed to allow for the practice of euthanasia and/or physician-assisted suicide, the medical profession must be involved in the development of relevant legislation, regulations and guidelines which protect all doctors acting within the law; vulnerable patients; society; patients and doctors who do not want to participate; and the functioning of the health system as a whole.

I do not want to appear as though I am not trying to cooperate with the committee, but that was a big change from the previous position statement. The AMA recognised that we may move on to this situation and wish to be involved at that point should the Legislative Assembly, in this case, move to it.

MS CHEYNE: I think that is a critical distinction to draw. Finally, in relation to the AMA's position on decision-making capacity, in your submission you touched on competence and age. I believe in some jurisdictions, like Belgium, it was not so much about letting kids just go rampant with accessing the scheme but much more about age being really an arbitrary distinction in terms of someone's competence or their decision-making capability. I just wanted to draw out your thoughts on that.

Dr Bikshandi: There is actually a substitute decision-maker clause in it, but it is a very difficult question, as the phrase "compos mentis" is most variable in its definition. What is "compos mentis"?

I come across situations where two groups of people exist: next of kin versus surrogate decision-makers. They are not necessarily the same. In relation to the surrogate decision-maker, when we should rely on their decision-making, "agent" is probably an easier thing to deal with; we can say that at this stage they cannot. When they are beyond the legal decision-making age, when can surrogate decision-makers—whether the decision is valid over the individual is through an individual case-by-case analysis. There are some diseases where you can certainly say that the patient is comatose and they cannot make a decision; it is very obvious. There are some situations where mental illness does not always affect what is compos mentis. There are some mental illnesses which affect compos mentis, as we call it: a dementia, for instance, where someone is not able to retain what we say or provide a logical answer. I think it should be on an individual, case-by-case basis. But who determines it?

At present, as things stand, it is usually the medical practitioners, with reasonable association in an acute-care facility or elsewhere, in the belief that they are compos mentis or not. That is the standard practice. Many times we get a surrogate decision-maker's opinion when we think the patient is confused enough not to make a sensible judgement. In the absence of a surrogate decision-maker, we consult the state guardian. It is a difficult thing to establish what constitutes compos mentis and who is the final determiner of compos mentis.

THE CHAIR: I would like to thank you both for appearing in front of the committee today. It has been very interesting. When available, a proof transcript will be forwarded to you to provide an opportunity for you to check the transcript. With any questions taken on notice, the committee is asking that they be provided to the committee within 14 days of receipt of the proof *Hansard*.

HEINE, MRS MICHELLE
HEINE, MR KEVIN
HIGGS, MRS MARIE
HIGGS, MS PHILIPPA

THE CHAIR: I welcome our next witnesses to today's hearing. Before we get started, can you all confirm for the record that you have read and understand the privilege implications of the statement in front of you?

Mrs Heine: I can confirm that.

Mrs M Higgs: I confirm, thank you.

Ms P Higgs: I confirm.

THE CHAIR: Thank you. Before we proceed to questions from the committee, would you like to make a brief opening statement?

Mrs Heine: Do you have copies of the submission in front of you?

THE CHAIR: We do, yes.

Mrs Heine: I guess I do not need to go through it. I am representing the Higgs-Heine family in the death of Phillip Rudolph Higgs on 9 January 2018. We are here united as a family in the push for assisted dying to be legalised in the ACT. We were totally unaware as a family group about what actually happens when someone becomes so gravely ill and is close to death.

Firstly, he became seriously ill over the festive season, which put him on the back foot as there was only a skeleton staff looking after him and the other patients in ward 4B. Secondly, we were not informed by the hospital staff about the actual fact that Phil was too far gone for treatment until we demanded to see a doctor so that they could tell us what was going on.

Phil told my mother that he did not want to live anymore. Later that day he pulled me close to him and said, "I have had enough. I do not want to live anymore. I want to die." My father is a fighter and to hear him literally beg to be allowed to die broke my heart. You could see the desperation in his eyes and we were helpless to give my father the closure he desperately wanted.

A parent protects their children all through their life. Yet in his time of need we were unable to protect him and reciprocate the help he so wished for. Once we were told that our attempts to force-feed were, in fact, detrimental to him, we all felt like we were slowly leaving him to die an unnecessarily painful death.

This is something that tore us apart. We do not ever want to see another member of our family, friend or anyone in the ACT go through this kind of excruciating death. It is traumatic for the dying patient but also for the family watching on hopelessly as it is happening.

Once the prognosis was made that there was no hope, we felt that we should have been able to say our goodbyes and watch him fall into eternal sleep, to be asleep without pain. I vowed after seeing my dad die that I would become an advocate for euthanasia and that I would do anything to see it become legalised in the ACT.

This type of peaceful and humane ending would have made his death more acceptable to us all. However, we all feel guilty that we could not have done more for Phil in his final days. The way he suffered in those last few weeks will remain a burden on all of our hearts forever, more so than the actual cancer that killed him.

We euthanise our pets in their suffering and it is time to allow our loved ones a chance to die in peace and with dignity. So, please, we beg of you: heed people’s comments.

THE CHAIR: Before we continue to questions, at any time if you need us to pause or to suspend the hearing, please let us know. We know how distressing this is. We are not here to make that harder.

Mrs Heine: Thank you.

THE CHAIR: I think that moved all of us.

MRS KIKKERT: My sincerest condolences to you and your family. I am sorry about your loss. Thank you for being here this morning. My question is about your grandfather. Did he eventually die at Clare Holland House or was it at the hospital?

Mrs Heine: We fought very hard to get him into Clare Holland House. None of us was aware that there are only 19 beds available in the ACT, which was a real shock to all of us. I just could not grasp that concept. I thought the 19 beds they spoke about were just for the Canberra Hospital, but then I found out that they are for the whole of the ACT.

I went and visited them. I put in submissions and spoke with the staff at the hospital. We just kept being pushed back, “No, no, no, no, no, no, no,” until eventually we asked the minister to come and read the last rites to my dad. He came back the next day and said, “What is going on?” That is when we explained what had been happening in the lead-up to the situation we were in. Within 45 minutes of speaking with him, we had had a call to say that there was a bed for him. They said, “We will send an ambulance at 5 o’clock.” He said, “No, send the ambulance now.”

The staff felt that my father would die in the ambulance. I said that then we would have helped him with his final wishes, which were, “Please do not let me die in hospital. Please do not let me die in hospital.” Even though my dad worked at the hospital for many years and it was a very special place to him, he did not want to die in a hospital bed. Probably by lunchtime on the Monday we had him at Clare Holland House. We got to spend some beautiful time—a couple of hours—under the gazebo with him. Then he passed away the next morning at eight. We at least kept part of our bargain to him.

MRS KIKKERT: And he would have been so proud.

Mrs Heine: Yes.

MRS KIKKERT: Thank you for doing that. Did morphine help him at the end when he was in hospital?

Mrs Heine: We were not told—they were coming in every four hours. After two hours, my dad was very agitated. We were not told at the time that he could have had morphine at any time of the day. He could have had it 24/7. We were not told these things. There were so many things we were not told in the hospital. Yes, eventually he was on morphine all the time.

MRS KIKKERT: Having gone through the experience that you went through with the hospital and also Clare Holland, what would you recommend for improvement in both cases?

Mrs Heine: For me, definitely more places like Clare Holland House. I cannot tell you the difference it made to our family. The minute we walked through that front door at Clare Holland House, I felt such relief at the fact that he was actually there. The staff are incredible. They are absolutely incredible at Clare Holland House. I just wish he could have had a bit more of that and not just literally have gone there overnight to die.

Mrs M Higgs: Could I also make a point?

Mrs Heine: Yes, go on.

Mrs M Higgs: If a person is terminal, as he was, the only indication we got to say that there was no hope for him was when I asked the ordinary doctor on the rounds. I said, “My son lives in Singapore. Do I send for him?” He said, “Yes.” That is the only thing they said to us. “Yes, send for your son.” But they do not tell you, “We are going to withhold liquids. We are going to withhold food. We are just going to let him starve to death and his organs shut down.”

To me that is so cruel, so very cruel. There should be more communication when there is no hope. They should tell the family that this is how it is going to go, this is what it is going to be like. But here we were with a syringe squashing liquid into his mouth, trying our best to keep him strong and we were doing the wrong thing.

MRS KIKKERT: How long was he in hospital for before he was transferred over finally to Clare Holland?

Mrs Heine: He was in for six weeks.

MRS KIKKERT: And with no proper communication with family members during those six weeks?

Mrs Heine: At the end we knew that there was something wrong with my dad because he was just so unresponsive. He was being aggressive and just not himself. We knew that this was not him. The doctors would come around and they would say that they were going to do this and they were going to do that. Then they kind of stopped coming around. They would not come around as often as they used to.

One day—it was at 9 o'clock that morning—we said, "We need to see a doctor. We need to know what is going on." We literally stood in the doorway. My dad's room was right by the nurses station. We stood in the doorway looking at them, like, "Please!" The doctors would see us and they would disappear.

Eventually, at 5 o'clock that day, we literally had to drag a doctor into the room and say, "What is going on?" They said, "There is no hope for your father." We wanted to know why they were not putting him on a drip because he was not eating. We kept asking; for three days we kept asking, "Can you put him on a drip?" No-one said anything. The nurse would say, "We would have to go and check with a doctor." No-one actually came back to say, "This is the situation." That is why every time my father literally opened his mouth or his eyes, we had the syringe and we were just trying to feed him to give him the strength to fight because, probably a few days before this happened, we had said, "Dad, if you want to go, if you need to go, you need to say to us that it is too much."

This was after he had said to both of us that he did not want to live. We said, "You have to let us know. If you want to fight, we will fight with you but if you want to go, you have our blessing to go." He said, "I want to fight; I want to fight." He was just so conflicted in how he was feeling. I think part of him wanted to fight for us. But the doctors just did not tell us what was going on.

We sat there with him saying that we should stop feeding him because we were doing him more harm. We had been researching trying to find products because we noticed he had a cough developing, a lot of phlegm in his chest. We discovered that that was part of our actually feeding him. It was detrimental, but we did not know that he was starting to choke on his phlegm.

I know how I felt. I felt like I was murdering my father, basically because everything that we were trying to do, which is human nature, was the wrong thing. But no-one told us. No-one told us about what happens when a person dies, when their organs shut down. We were never told that. Everything we found out was on Google, literally. When they said, "We are withholding food and water," I just went, "What! I do not understand." We had never experienced a close death before. To be told that they were just going to stop feeding and providing water to your parent, it was just—I just felt criminal.

MRS KIKKERT: I am truly sorry.

Mrs M Higgs: He lost his speech quite a few days before he died.

Mrs Heine: On 24 December.

Mrs M Higgs: In December he lost his speech. He could not convey anything. He could not tell you he had pain. He could not say anything. He would sit bolt upright in bed. He yanked out his drip. He pulled out the catheter. He was in such a terrible state and honestly I just felt the support that we had was zero, really zero.

Mrs Heine: Which is why we spent the last five nights, six nights in his room.

Mrs M Higgs: In the room with him.

Mrs Heine: Because we felt we were the only ones who were really doing anything for him. It was like he was a lost case because we could not get him into Clare Holland House. When the nurses came to prepare him to get ready to go in the ambulance, we were all in the room, and they said, "I don't even think he is going to make it in the ambulance, let alone out of this ward." This was in front of all of us and the grandchildren. We were just like, "What?"

My brother went with my dad in the ambulance and my dad knew, I think, he was being moved because he grabbed on to the railing and he held on from the hospital literally all the way to Clare Holland House. And I would have been happier knowing that he had passed in the ambulance as opposed to in that hospital bed.

We found that we were just fighting, fighting, fighting the whole time. You have got this anxiety and stress of seeing your father and your husband just deteriorating but there was just no support until the chaplain came in and then he literally moved miracles. In literally one hour, our entire lives turned around completely.

MS CHEYNE: Who was telling you "no"? You mentioned that until the chaplain intervened you were told "no" in terms of moving him to Clare Holland.

Mrs Heine: Yes.

MS CHEYNE: Was that Clare Holland telling you "no" or the hospital?

Ms P Higgs: The social worker—

Mrs M Higgs: The social worker said—

Mrs Heine: The social worker said there were no places but I guess she was in contact with them. Even that morning I had rung the organiser, the head, of Clare Holland House literally begging that he could be moved, and I was told emphatically, "I'm sorry, there are no beds whatsoever." That was at 9 o'clock that morning. And then once the chaplain came in, we already knew by 11 o'clock my dad was going to be moving after he had stepped in.

We had social workers, we had people suddenly just descend on that room. I would go, "Why didn't we have that beforehand? Why didn't somebody explain death to us?" Honestly, we had no idea. My dad had the death rattle for four or five days. To sleep in a room and hear this 24/7 is heartbreaking. He also stopped breathing for 40 seconds. Every time that happened, we would sit bolt upright thinking, "Is that his last breath?" We did not want him to have his last breath without us being there touching him.

We did everything. We had music playing, all his favourite music playing. We had all these essential oils in the room. We had candles. We had everything. We just tried so hard to make him realise that we were there and we were trying so hard to help him.

There were a couple of individual nurses that were phenomenal, absolutely incredible; in general, if the doctors do not have the time to speak to the family then there needs to be somebody else. There needs to be another process in place because the doctor said, “Stop feeding him, no eating,” and she just left the room and we were like, “What?” That was basically it. We did not see a social worker. She was not in there. We did not see her until that last day. Everything was traumatic. It was at Christmas-time when there was absolutely skeleton staff on, when he was not getting physio, and the doctors were not doing the rounds obviously as often as they did.

It was just one thing after another. It was just a bad series of events for us. I personally cannot get over his death because I feel, if I had known more, I would have been able to try and help him. I do not know if I could have but that is how I feel very guilty about my father’s death. That is something now that I have to live with.

But if we can stop somebody else going through what we went through, that is where we are at the moment. We cannot help him but he can be the person that pushes us to make a change.

Mrs M Higgs: And I would like to just say the oncology department would have been far more helpful because they knew the cancer had gone to his brain. He even had a seizure, and they could have said to us right from the word go, “He has got no longer than 10 days,” five days, whatever it is, “but this is what we’re going to do. We’re going to withdraw everything.” He would have no liquids, he would have no drip, no nothing, and we were just biding our time waiting for his organs to shut down. If they had just told us what to expect, I think it would have been a lot easier, and I do think it should have come from the oncology department.

THE CHAIR: I have two very quick questions. I have hundreds more. We have had lots of witnesses appear. Were you offered palliative care support? I am assuming this is at the Canberra Hospital.

Mrs M Higgs: Yes.

THE CHAIR: Were you offered palliative care support that you are aware of?

Mrs Heine: I think that one social worker did mention it to us, but she said, “You know it’s very difficult to get in,” and this one is waiting and this one is waiting, and you accept you are not going to have much chance of getting your loved one in there at all.

Mrs M Higgs: Most of the time I got the distinct feeling not to get our hopes up because—

THE CHAIR: There was no palliative care provided at the hospital; is that correct? To your knowledge?

Mrs Heine: No.

Mrs M Higgs: No.

MRS DUNNE: That is part of my question. Mrs Higgs, you were saying that you thought that as the primary providers of treatment the oncology department did not prepare either your husband or your family for what was happening?

Mrs M Higgs: I would like to say: when they said that the tumours had started to reach the brain, they said, “The only other thing we can do now is radiology.” And I did ask one of the staff there, the oncology staff, “If it was your father, what would you recommend?” And she said, “No radiology.” That was what took his speech. But it was his call. He wanted to buy just three weeks. He just wanted to buy three more weeks.

MRS DUNNE: And in one of your submissions, I do not recall which one, you said that he had a lymphedema in his leg and he was given no treatment. There are physiotherapy-type treatments for that. He received no treatment for that?

Mrs Heine: When we got him to the hospital, when he was in ICU, that is where we discovered all these garments, and that there was an actual—

MRS DUNNE: The brace?

Mrs Heine: proper drainage massage available specifically for this. His leg pretty much felt like a piece of wood. There was no pliable movement in his leg whatsoever until he got into ICU and then, whatever medication they gave him and with using the garments, it started to soften up.

THE CHAIR: Was he at home before ICU or was he already in the hospital?

Mrs Heine: No, he was at home.

Mrs M Higgs: Yes, he was at home.

Mrs Heine: And he collapsed twice, yes.

THE CHAIR: I did read that in the submission. I just wanted to refresh my memory.

MRS DUNNE: The chain of events was that he collapsed at home and he went to accident and emergency and was there for—three days?

Mrs Heine: The first time he collapsed was when they did the scans, when they discovered that it had moved to his brain. That was when we had the discussion about the radiation. He had one treatment of radiation, and that night he developed cellulitis in that leg and high temperature. He was in emergency for a day and then ICU for three days before going into the—

MRS DUNNE: At any stage after he came out of ICU was he offered the opportunity to go home with community support?

Mrs M Higgs: They kept putting a date on the board saying, “This is the date of discharge.” And that is what I said to my son—I could not handle him at home, because he needed a sling to get him into the shower and it would have been totally impossible for me to handle him at home.

MRS DUNNE: Was there a discussion with you as a family group—

Mrs M Higgs: Not as a family, no discussion. Just on that whiteboard, date of discharge, such and such a date, and then every day they might change it or every two days they might change it.

MS LE COUTEUR: But they did not discuss with you the state in which he would be discharged and your ability to—

Mrs M Higgs: No, they said—

Mrs Heine: No. They did say, “Do you want to find out about home care?” We said, “My mum will never be able to handle my father.” There was no way on this heaven and earth that he could have gone home. There was just no way.

MS LE COUTEUR: Did you end up starting to look for nursing homes or did it happen quickly enough that you did not go through that stress as well?

Mrs Heine: He did not want to go to a nursing home, and that was when I started to look into Clare Holland House, because he did not want to. I was also looking to find out whether there was a way of paying for a private nurse to have him at home, but it would have to be somebody who would have to stay there because my dad just could not help himself.

MS CHEYNE: Your experience is very similar to my own in terms of my father trying to buy time. It took too long for someone to tell him that time-buying is a stupid idea, but also the ripping out of the catheter, the death rattle, the no ingestion, the playing music and trying to comfort brought back a lot of memories for me. And also googling; I was a big googler, trying to determine what the final hours look like, so that I would be there.

Mrs Heine: Just so we had an idea of when it was going to happen.

MS CHEYNE: And no-one really tells you. In my case, I was really lucky to have a doctor I did not personally warm to, but at least he said to me, “These are the signs that this is the end.” And when that happened, my mum rang and said, “Get here,” and that was very fortunate.

This is a difficult question and I hope I am not asking it indelicately, but we have heard some people intimate—and I think we see it in the media as well—that there is something noble in dying a natural death and even in suffering in death and that it can make families stronger and that by going through a difficult or traumatic experience it can make someone stronger. That does not seem to be your experience. I do not want to put words in your mouth but, Mrs Heine, you mentioned that the memory of how he died is a burden on all of your hearts, and the guilt that you feel. It is a difficult question for me to ask, but it is important for our work if you take a moment to reflect on—

Mrs Heine: I do not feel stronger at all. There was nothing good about the end for me. We were a very strong family beforehand. I think it just broke all of our hearts, the way that it ended. I did not see any benefit in his last few weeks.

Ms P Higgs: It is awful watching someone gradually get weaker and weaker and weaker. That is not how I want to remember my father. I would much rather remember him when he was still in a reasonable state. What he became at the end, that is not him, and I do not want to remember that time. I would much rather have given him the option and for him to go when he still had some dignity. Just turning up to hospital every day, day after day after day after day after day, does not make you stronger. It definitely does not make you stronger.

Mrs Heine: We spent Christmas Day celebrating in the hospital with him. We were there every single day from the minute he was put into emergency. We were there 24/7 for him. I know my daughter one day could not even go into the room. She just said, “I can’t see Pops like that. I just can’t.” The memory the grandchildren have and that we have is not the memory you really want to have.

Mrs M Higgs: When they lose their speech, really, that is terrible.

Mrs Heine: You cannot communicate.

Mrs M Higgs: Because you can see the absolute utter frustration; he wanted to get something out but he could not get it out.

Mrs Heine: He could not write either.

Mrs M Higgs: That to me was the worst—he could not communicate.

MS CHEYNE: To frame the question slightly more positively—I think you touched on it as well, Ms Higgs—what would a good death have looked like for you and your family, and with your father and your husband?

Mrs Heine: For me, when the doctors came to us and said, “There’s no hope. He’s never going to get better. He’s actually just going to pass away,” I would have preferred at that point in time for us to have had something together as a family—wherever he was, had a little moment together—and then have him euthanised, so that he would then have just peacefully slipped away. We would have all been there supporting him, and he would have known that we were there. I think he would have understood that, because he said to us that he did not want to live anymore.

Mrs M Higgs: Practically his last words were, “I want to die.” After that, he never spoke.

MS CHEYNE: Is that description true for each of you?

Mrs Heine: Yes.

Mr Heine: I was not here; I was in South Africa at the time. But I was living through the process from the messages that were coming through. My brother-in-law is a minister, and when he heard that they were going to stop the liquid and stop the food he said, “That’s murder.” They were his words. In reality, it is legal murder, as opposed to euthanasia. Listening to the doctors earlier when they were talking about legal liability and mental stability, if you are at that stage where you want to die, you should have the ability to say, “Yes, I want to be able to pull the plug.”

THE CHAIR: Should it be your choice to ask for that? Some of the witnesses we have heard from have raised the issue of elder abuse. I know you said how old your father/husband was, but should it be the person’s choice that is terminally ill?

Mrs Heine: Yes.

Mr Heine: Yes.

THE CHAIR: Not the family’s choice?

Mrs Heine: Yes.

Mr Heine: Yes.

Mrs Heine: It was his choice, yes.

Mr Heine: Yes, his choice initially. But he should be informed that, “There’s no hope. You’re not going to make it. These are your choices.” And the next stage that comes up is if they get beyond that stage and their mental abilities and cognitive aspects of their life have gone, then the family should have some say in it. I can understand the legal aspects, but there are certain times when moral and ethical standards trump legal liability. At what point does that happen?

Mrs Heine: The decision to remove the food is essentially back-to-back with euthanasia because basically the doctors euthanised him, but slowly and painfully and it was hurtful. To me it is the same thing but—

Mrs M Higgs: Inhumane. Totally inhumane.

Mrs Heine: It is just they are back-to-back.

MS LE COUTEUR: I am interested in whether you have any more views as to how euthanasia could have happened in your father’s circumstance. If you look at the Victorian legislation, as I understand it, in your father’s circumstances he would not have been eligible mainly because of the amount of time it would have taken from when he decided he wanted to get all the paperwork done. He did not have enough time to do all of that.

Mrs Heine: But that was never an option on the table. If it had been an option, if it was legal, we would have discussed it when he first got sick.

THE CHAIR: As a patient and as a family?

Mrs M Higgs: And as a family.

Mrs Heine: Yes, as a family. Pretty much everything that happened with my dad, it was his final choice, but we were all part of those discussions.

MS CHEYNE: We have heard evidence from some people about elder abuse and pressure from family members.

Mrs Heine: I can imagine.

MS CHEYNE: But one of you gave evidence before that whatever his wishes were, they were ultimately his wishes and you would support that in any way.

Mrs Heine: Absolutely. After we discovered it had moved to the brain he was told the prognosis was three to six weeks without radiation or three to six months with radiation. I think mum was probably more for not having the radiation. I was just happy with the way dad just wanted to fight. He just wanted six more months with his family. That is all he wanted, and we supported every decision he made. As I said we are a very tight-knit family and we supported him throughout the whole process.

MS CHEYNE: If voluntary assisted dying had been available to him and he had still decided not to go through with it at any stage and had still suffered the same death, do you think there still would have been some positive impact because he still would have been making a choice?

Mrs Heine: He would have made that decision.

Mrs M Higgs: It was his choice; to die on your own terms.

Mrs Heine: I think that is what this is all about—to be able to choose.

Ms P Higgs: Once he was so heavily medicated, he was just lying there.

Mrs M Higgs: Yes, he was a vegetable, actually.

Ms P Higgs: I think he would have preferred to have made the decision while he could still sit up and was still conscious and had a bit of speech.

MS CHEYNE: And he still could have said, “Actually, no. I’m prepared to go ahead with this,” but perhaps the lasting guilt some of you have said you feel may have been lessened.

Mrs Heine: Yes.

Mrs M Higgs: But his last spoken words were, “I want to die.”

THE CHAIR: On behalf of the committee we really appreciate you coming in and talking with us.

Mrs M Higgs: Thank you very much for hearing us.

THE CHAIR: When available, a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections, if required.

Hearing suspended from 12.27 to 2.01 pm.

BOESEN, MR MICHAEL
GARFIT, MS JUNE

THE CHAIR: Welcome back to the after-lunch portion of today’s hearings for the end of life choices select committee. I welcome our next witnesses. Before we get started, could you confirm for the record that you understand the privilege implications of the pink statement on the desk in front of you?

Mr Boesen: Yes.

Ms Garfit: Yes.

THE CHAIR: Thank you very much. Before we proceed to questions, do you have a brief opening statement you would like to make?

Mr Boesen: Yes, I do. This would run at close to seven minutes. I am Michael Boesen. I am appearing here as a private citizen.

THE CHAIR: Thank you so much, Mr Boesen. Much appreciated.

Mr Boesen: First of all, we express our appreciation for the very valuable and very important work that the committee is undertaking and the chance to appear before it. My companion is June Garfit and she will correct me if I make any goofs. We represent 12 senior citizens who signed our submission. I feel that the views we have expressed in the submission would be endorsed by many other people, especially senior citizens.

Our views expressed in that submission are determined by our desire to have a good death when the time to say goodbye arrives. What is a good death? I am sure you are going to ask me what our view of it is, so here it is. The timing, location and manner of ending life is made by the person concerned, of course after consulting with relevant health professionals. The person can end their life irrespective of whether or not they have an incurable or terminal illness, and irrespective of whether or not they have a very limited life expectancy.

The person can end their life at a location of their choice: in their own home, hospital, palliative care facility or elsewhere. The person is not forced to have their life prolonged pointlessly. The person can avoid pain, discomfort and intolerable indignity. The person can end their life through a drug that ends life reliably, quickly, peacefully, painlessly and without discomfort or distress. The person can have assistance and comfort from friends and relatives when they end their lives, and they are able to say goodbye. The person is able to end their life when they see it as being the time to go.

How does that relate to the committee’s terms of reference? I turn to current practices for managing end of life. In the ACT options for ending life do not meet the needs of many people, especially many seniors who are fearful that they will not have a good death. The options are, as you would all know, dying at the end of palliative care undertaken in an institution or, in a limited number of cases, at home.

We support the provision of palliative care facilities and services. They do a wonderful job. For many people that is an acceptable option. In many cases it leads to a good death. But there are others who fear a protracted, drawn-out process under palliative care and can recall instances of bad deaths.

The shortcomings of palliative care have been identified in a number of the submissions so I will not list them all. But two points seem very important. It is indicated by a number of palliative care nurses and doctors that it is not always possible to provide effective management of pain and suffering. For many people the time spent in a palliative care institution is pointlessly long. It is obvious that the New South Wales or Victorian systems for voluntary assisted dying—I will call it VAD, if I may—would be of great value if their provisions were to be implemented in the context of the palliative care process. So both those models would be of great benefit in palliative care.

But if a person wants an alternative to the current system of palliative care, what can they do? They can go to another country, which is not a feasible option for most, certainly not for me and I do not think for June. They can commit suicide by drugs or other means, and that is not a feasible option for most people and can have grave dangers.

These are the community views on voluntary assisted dying. In Australia there is overwhelming support for VAD for people who have an incurable terminal illness or are in unrelievable pain. That is the term that is used—or a term close to that—in a number of surveys that have been done since 2007. They show consistently that 70 per cent to 80 or more per cent support VAD for such people.

For people in extremis, the question about appropriateness of voluntary assisted dying has been answered, and answered for a long time. It is a no-brainer. However, the questions that have not been asked in such studies and surveys, polls, is how the community feels about VAD for people other than those in extremis. We believe that a survey, a properly constructed and designed survey, should be undertaken to determine such views. I would be happy to provide assistance.

What are the risks with VAD? A number of risks are always identified by the very vocal and well-organised minority of people who are still opposed to voluntary assisted dying. We have the slippery slope, coercion of elderly and vulnerable, incorrect assessment of mental capacity, condoning of suicide, and on and on it goes.

But in the many years since 1997, when it came into effect in Oregon, there has been provision for voluntary assisted dying in about 16 jurisdictions comprising more than 200 million people. The studies of the operation of those systems have indicated that the risks have not been realised. There is abundant evaluation and research that proves the risks have not materialised, contrary to the misinformation by those opposed to involuntary assisted dying and in some of the submissions that you have received.

There is an excellent, very short, readable review of overseas voluntary assisted dying systems by Professor Penney Lewis. I recommend a close read of that study. Penney Lewis is Professor of Law at King’s College London. It is a very elegant, well-written and well-researched summary of the situation, which as I say concludes that the risks have not been realised.

What is the applicability of voluntary assisted dying systems in other jurisdictions? The Victorian system is based on the very restricted Oregon model. For many people the Victorian model would be of enormous benefit because at least there are some people who are in extremis who could have a good death at the end of life. The New South Wales system is very similar to the Victorian model—some slight fiddles with some of the key criteria. But again it is for people in extremis.

Some people may not have a terminal illness or may have a life expectancy which is greater than six or 12 months—people such as those suffering from untreatable chronic pain or with ongoing debilitating, untreatable ill-health and so on. There are many people who are not going to die within six or 12 months and who do not have what is classed as a terminal illness. They feel awful. Their life is awful. At some stage they become tired of life and feel it is time to go.

There are more permissive models than the New South Wales and Victorian systems. The one that really appeals to us is the Netherlands model. That has been going since 2002. It does not have in its required procedures and situations the criterion of an incurable illness or a time left to live.

The handout that Andrew is giving you summarises the elements of the Netherlands model. I came across that after we had put in our submission. I was pleasantly surprised to find that that model is one which had very similar elements to what we propose.

In conclusion, we believe that there should be access to provisions for voluntary assisted dying to be undertaken at a time and location of a person’s own choosing, but without regard for whether or not they have a terminal illness and irrespective of their life expectancy. We have provided details of that model in our submission.

Incidentally, we see that as being a human right. The ACT Human Rights Commissioner also sees it as a right. She said that “the Victorian model imposes limitations on human rights, including the right to equality, as it excludes people under 18 and people experiencing suffering that cannot be relieved but who are not assessed as expected to die within six months or 12 months if a person has a neurodegenerative disease.” So our Human Rights Commissioner, like we do, says that we have a right. June, have I missed anything?

Ms Garfit: No, I think that is what we were discussing and talked about.

THE CHAIR: Thank you, Ms Garfit. Could you introduce yourself?

Ms Garfit: I am now an Australian citizen. I was originally English. I have lived in the ACT for around 52 years.

THE CHAIR: Thank you. Are you ready for questions?

Mr Boesen: Yes, I hope.

THE CHAIR: Thank you both for coming in and being here for the committee hearing today. It is very much appreciated. I want to pick up on one of the points you made, both in your submission and in your opening statement, and that is what you said about the Victorian model:

> We believe that having a terminal illness should not be a prerequisite for access to voluntary euthanasia because it could be an inappropriate criteria.

Mr Boesen: Yes.

THE CHAIR: I am wondering how that may impact people that are suffering from psychological or mental health issues.

Mr Boesen: We also stated as our first criterion that they must have fully competent decision-making capacity. That is, I think, an answer to your question, or is it not?

THE CHAIR: What about people that are suffering from depression? They could be quite mentally capable of making decisions but their decisions could be altered because of their emotional state?

Mr Boesen: Where we come out on that is that, if a person is suffering from a number of medical problems, they can become depressed and they become fed up with their situation. I do not know if one would class that as depression or not. Our view is that, if a person has consulted appropriate medical practitioners about the probable causes of their depression and options for treatment, if they have a good understanding about causes and treatments, if they give full consideration to, and have trialled, treatment options that are available, if they decide that they do not wish to undertake any further treatment for depression, and if the person legally has a decision-making capacity, why should they not also have access to voluntary assisted dying?

THE CHAIR: So you are really just saying it is an individual choice?

Mr Boesen: It is the patient’s choice, yes, providing they have decision-making capacity.

THE CHAIR: Yes.

Mr Boesen: And providing they have information then it is up to them; yes.

THE CHAIR: Fantastic. Thank you so much. Mrs Dunne?

MRS DUNNE: Thank you very much for attending today. I would like you to expand, if you could, on the points that you make in your submission that the jurisdictions that we see in operation overseas have enough protections and that the concerns raised by people that you characterise as opponents of euthanasia are not justified by the experience in, say, the Low Countries or in Oregon or elsewhere?

Mr Boesen: Yes.

MRS DUNNE: You said that there are sufficient protections.

Mr Boesen: Yes.

MRS DUNNE: Can you substantiate that from your research?

Mr Boesen: I suggest that you have a very close read of the Dying with Dignity New South Wales submission. It has a tonne of information which reflects on that issue. There is also an excellent submission made to the Western Australian inquiry by a man, whose name escapes me at the moment, which also goes into the same analysis. As far as I am concerned—and my background is in doing survey research and research methods—the rebuttal of the claims that are presented particularly in those two documents, plus Penney Lewis's analysis of all systems that are in operation, thoroughly convince me that the fears are groundless.

I would also point out that we get misstatements and mistruths from opponents of voluntary assisted dying. For example, a classic one is that Els Borst, who is the minister in charge of getting the laws accepted in the Netherlands, has said she regrets it. She has never said that, and she has said that she never said it. Theo Bors is another person—another Netherlander—and it is stated that he had a massive conversion away from voluntary assisted dying and he says, categorically, he was always a sceptic. Daniel Mulino continues to put in his minority report claims that are just not substantiated by rigorous statistical analysis.

The submission by Neil Francis to the parliament of Western Australia's joint select committee on end of life choices—I have a copy of it here if anybody wants to have a look at it—is a must-read in my view, as are the attachments to the Dying with Dignity New South Wales submission. They are chock-a-block full of good information that one must have a look at.

MRS DUNNE: Which parts of Daniel Mulino's minority report in your view—and I am happy for you to take this on notice because it would require some analysis unless you have it in front of you—is not substantiated by the evidence?

Mr Boesen: I can give you an answer to that, I think.

THE CHAIR: Perhaps on notice, given the time.

Mr Boesen: I will come back to it.

THE CHAIR: Are you okay with that?

MRS DUNNE: Yes, absolutely.

Mr Boesen: The reference I gave you points out there are at least four major problems with some of the analyses that Mulino has undertaken. The person then talked to Mulino about it, and Mulino admitted that he was wrong. That is what the person indicated. Again, with Neil Francis, I have taken what he said at face value. He may be misrepresenting—

MRS DUNNE: When you say that there are problems with Mr Mulino's analysis, it is not your analysis of Mr Mulino's analysis; it is you reporting somebody else's analysis?

Mr Boesen: I have taken at face value what Neil Francis says, yes.

MRS DUNNE: That is fine. I just wanted to clarify your position.

Mr Boesen: If I had more time, I would have done my own analysis, yes.

MS CHEYNE: I will declare that I have met Mr Boesen before during the 2016 election campaign in Weetangera. Mr Boesen, you have largely pre-empted all my questions but I did want to ask about something you have not touched on. Very briefly if I may, there are some claims that physician assisted deaths lead to a contagion of suicide. Do you have any evidence or any comments on that, particularly in the conversations that you have had in your community?

Mr Boesen: Yes, I do have comments. Firstly, Penney Lewis, Kings College London, with the analysis she has done, says categorically there is no slippery slope.

Ms Garfit: Yes.

Mr Boesen: That is my first response. And I think that pretty much sums it up. If you have a look at analyses done by Neil Francis, they would support that as well.

THE CHAIR: Thank you so much.

Mr Boesen: Do I get a tick on the other questions?

MS CHEYNE: We might put some on notice.

Ms Garfit: May I add slightly to that?

THE CHAIR: Yes, certainly.

Ms Garfit: I have in front of me the report by Penney Lewis, Professor of Law, King’s College. I do not know if you have it available.

Mr Boesen: No.

Ms Garfit: It is very comprehensive about what she has looked at.

THE CHAIR: Would you like to table that?

Ms Garfit: Thank you, I will.

MS LE COUTEUR: I should acknowledge that I have known Ms Garfit for quite a few years. I am not quite sure how many.

Ms Garfit: Thirty, maybe.

MS LE COUTEUR: I have two questions to ask, both of which I can reference to euthanasia in the Netherlands. The dot point says:

> The request cannot be granted when under the influence of others.

This is something that we have talked about with a number of witnesses because the issue of potential elder abuse has been brought up, as you can imagine, by many people. The question has been: when can you be confident that the person requesting voluntary euthanasia is not under an abusive influence—from their relatives, usually? I was just wondering if you had any more information about how the people in the Netherlands might deal with this very important issue.

Ms Garfit: It is a difficult one. Coercion can be done at home and can be done privately, and all sorts of reasons given to granny or grandpa as to why they should end their lives. Perhaps there are two things: you have medicos who are talking with the person who has wished to terminate their life and you have, where needed, psychiatrists also evaluating the state of mind—they are trained psychiatrists—particularly to find out whether you are stating your own opinion or what you have been told to say. That is how I would answer that.

Mr Boesen: In addition, one of the provisions in the Netherlands legislation is that there must be consultation with at least one other independent doctor who needs to confirm the conditions that are mentioned above. You have at least two medicos who are making that assessment.

MS LE COUTEUR: And would they normally have to include a psychiatrist? One of the issues, I understand, with the Victorian legislation is that it does not.

Ms Garfit: They are in Victoria but I do not think so otherwise. It is just a doctor or two.

MS LE COUTEUR: The other question has been spoken about by some other people. You have talked about a person only making a decision if they are competent, but what about the situation where you made a decision that, if some circumstances happened, you would wish to end your life and at the point of those circumstances you are no longer mentally competent, which, I would imagine, is quite common. Do you have a view about the possibility of what is, in effect, pre-approval and how you would do the pre-approval?

Mr Boesen: I do not quite follow the question. You have somebody who is competent but then ceases to be competent?

MS LE COUTEUR: Yes.

Mr Boesen: If they cease to be mentally competent then they do not qualify.

MS LE COUTEUR: That is possibly the situation. It has been suggested to us that in many cases people will become mentally incompetent a few weeks before their end of life when it would appear that they probably would like to end their suffering but they are not in a position to say, "Yes, I want to," even though all the evidence before that would suggest this is entirely what they want. It is just they are not—

Mr Boesen: Some overseas systems place great store in an advance care directive.

Ms Garfit: Yes.

Mr Boesen: And in that situation, if a person were competent and expressed a desire for voluntary assisted dying and then, as you say, a couple of weeks before became incompetent, possibly if there is an advance care directive that might provide the evidence that is needed for a doctor or a medical person to assist in what is assumed to be the end. On the other hand, I really cannot say definitely what would apply in that situation. I would have to give that a lot of thought. But that is one of the sorts of issues that would need to be addressed in legislation, and I will leave it to you experts on that.

Ms Garfit: I would say a bit more. I would say that, in the advance care directive, I hope that they look at the hypothetical that right now I am making this decision because I am competent but in the event, for example, I have a stroke and I am not capable of thinking clearly anymore, I hope that the people in charge will go by what I instructed when I was capable. I am now speechless et cetera. But there are still ways of communicating. But if my brain is not understanding your question, I am beyond that. That is when I would like my life to be ended for me.

Mr Boesen: And in my advance care directive I state virtually that. June has an advance care directive as well.

Ms Garfit: And that is how I would look at that.

MRS KIKKERT: Thank you both for being here this afternoon. Can I just go back to this document on euthanasia in the Netherlands? The last point talks about the patient being at least 12 years old and that patients between 12 and 16 years of age require the consent of their parents. Do you believe in euthanasia for children?

Mr Boesen: I find the statement “Do you believe in euthanasia for children?” a little strong. What they have decided in the Netherlands is that if a patient is at least 12 years of age and with the consent of their parents then euthanasia is appropriate. In our submission, we would go along with 18 or more. Is an 18-year-old a child? I do not think so. I think they are entitled to vote and pay taxes and drive cars and run over people if they want.

Ms Garfit: And to be conscripted into the forces, for example.

Mr Boesen: Yes. Our view is 18 or more. Another wrinkle, I guess, in our submission is that we think that anybody who is over the age of 70 should have access to voluntary assisted dying. I know that that would cause argumentation but would you believe 80 or 90 or—like that chap who went over to Switzerland—104?

Ms Garfit: David Goodall.

Mr Boesen: We feel that at some stage in the life process you get to the point where you wish to die, and that should be enabled through voluntary assisted dying procedures.

Ms Garfit: Can I say one more thing?

THE CHAIR: Certainly.

Ms Garfit: I am partly here because I am a woman and a lot of the signatories in that submission are men's. I am not a signatory to that submission. I am partly here as a woman but I am also here as a committed Christian. I have been a Quaker for 50 years, and before that I was a Christian, brought up in the Christian faith, and I have heard too many people say, "All Christians are against voluntary assisted dying."

This is not true and, to support my claim on that, there is an organisation called Christians Supporting Choice for Voluntary Euthanasia, run by Ian Wood at Mittagong. I have some pamphlets. He is finding that some people of all Christian religions are saying they want voluntary assisted euthanasia. I would like to say that I am a Quaker. The Quakers are the Religious Society of Friends, Christians, and my Canberra meeting has joined in a group membership with Christians Supporting Choice for Voluntary Euthanasia. That does not mean, I emphasise, that all Quakers feel that way. I am just saying that the meeting of Canberra Quakers does feel that way and has joined. Those are my personal remarks.

Mr Boesen: Could I also just quickly say that if you have a look at Neil Francis's submission you will see that support for voluntary euthanasia applies across all Christian groups. And it is either strong or very strong support for it. However, the problem possibly is that the moral support is with the hierarchy rather than the members.

Ms Garfit: Can I distribute those to you, please?

THE CHAIR: Yes. I would like to thank you both for appearing today. When available, a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections. Thank you again.

DONNELLY, MR GREGORY JOHN, Member, New South Wales Legislative Council

THE CHAIR: I would like to now welcome the Hon Greg Donnelly MLC from the New South Wales parliament. Before we get started, Mr Donnelly, could you confirm for the record that you understand the privilege implications of the statement in front of you?

Mr Donnelly: Yes, I have read the statement and I do understand it.

THE CHAIR: Before we proceed to questions, would you like to make a brief opening statement?

Mr Donnelly: Yes. I have an opening statement; it will take about seven or eight minutes. I will work my way through it. Can I commence by thanking you for inviting me to appear before the committee. This is a most important inquiry and I hope that the evidence that I provide today, in addition to that I have provided in my submission, will assist the committee in its deliberations. As a member of the New South Wales Legislative Council, I too, as a legislator, have had cause to consider seriously the issues of assisted suicide, euthanasia and palliative care.

Regarding assisted suicide and euthanasia, I believe that we have a duty to our constituents to be clear in our language about what is being considered. As politicians we understand both the significance and the power of language. The term “voluntary assisted dying” that continues to be used in discussions around end of life matters is, with respect, done deliberately to shroud what is actually being considered. If what is being proposed is in fact assisted suicide and euthanasia, that is the language that should be used. Regarding palliative care, notwithstanding the deliberate attempts by some to conflate assisted suicide and euthanasia with it, it has no relationship with these practices at all.

As committee members may be aware, the New South Wales Legislative Council has considered proposed assisted suicide and euthanasia legislation twice in the last four years, the most recent in 2017. In both cases the bills were defeated. During both parliamentary debates I, along with my colleagues, received significant amounts of information and material from constituents and indeed those advocating a position on the matters. I note that this inquiry has also received a number of submissions and is hearing from a range of witnesses.

No doubt, as committee members are finding, the closer that one looks at these matters, the more one realises how complex the issues are. And of course there is the emotionally charged nature of what we will all face one day: the reality of dying and death.

In the end, though, from the point of view of legislators, we are required to confront and answer these questions, I submit: is it possible in truth to codify assisted suicide and euthanasia with guarantees and protections that we would want to see applied to such a monumental question, namely, the legal taking of human life? Is it possible to draft such a law to create a guarantee that would, for example, protect an old and failing body and mind from a quiet and hushed conversation behind closed doors with a close family member that perhaps one’s time has come and we can help let you go? I have come to the conclusion, after thinking about this matter a great deal, that the answer is an unequivocal no.

I turn to the issue of end of life care. A term perhaps we are more familiar with is palliative care. No doubt committee members are aware of the significant inquiry and report by the Productivity Commission entitled *Introducing competition and informed user choice in reforms to human services*. It was publicly released in March 2018, just recently.

Can I specifically draw to the attention of the committee chapters 3 and 4, from pages 109 to 169. The two chapters deal with end of life care in Australia and, I have to say, make compelling reading. I will not attempt to summarise in a few sentences what is covered in detail over 60 pages in an inquiry report but I do wish to quote one paragraph from page 112:

> Estimates of the proportion of people who could potentially benefit from end-of-life care vary typically from 50 to 90 per cent of all those who die … Given that just under 160,000 people died in Australia in 2015 … this suggests that between 80,000 and 140,000 people would benefit from end-of-life care each year.

Looking at the ACT specifically, it currently has a population approaching 420,000. The most recent published annual figure for registered deaths in the ACT from the Australian Bureau of Statistics was 1,839, and that was in 2016. The figure for 2018, I presume, will be around 1,900 or so.

From my investigations I have established that the ACT has only two full-time specialist palliative medicine physicians. I also understand that there are two registrars in training working in your health facilities. But that is just two full-time palliative care doctors, fully qualified, for a population of 420,000. Clearly, the ACT, along with other states and territories, is falling well short of the mark when it comes to providing appropriate resources, facilities and support for palliative care. Is it really no surprise that we therefore hear of tragic examples of some people experiencing a difficult and painful death? Surely, it is our primary responsibility as legislators to deal with this matter as a top priority. Just ponder for a moment: with such suboptimal provisional palliative care in the ACT and indeed elsewhere in Australia, how many individuals may decide to consider assisted suicide and euthanasia if a legislative framework was created for such procedures?

I also make a brief comment about the issue of elder abuse which I think is directly relevant to this inquiry. In my submission I refer to an inquiry undertaken in 2016 by the New South Wales Council’s then named General Purpose Standing Committee No 2, into elder abuse. I was the chair of that inquiry. I encourage all committee members to read the inquiry report that was tabled on 24 June 2016.

What we found regarding the incidence of elder abuse in New South Wales was, in a word, shocking. The inquiry drove home to me and indeed all committee members just how vulnerable and susceptible the elderly are to pressure and influence, ranging from subtle to out-and-out intimidation. And they are all the more vulnerable if they are frail, weak and mentally impaired.

The almost 500-page final report of the Australian Law Reform Commission entitled *Elder abuse—a national legal response* released in May 2017 makes for very sober reading for anybody who may have doubted that elder abuse is a major social problem in Australia in the second decade of the 21st century.

Finally, can I make a brief comment about suicide in Australia today. The figures are all too familiar and they are tragic. Human life is precious and, in my respectful submission, as legislators we should never support any legal initiative that would condone or facilitate people taking their own lives.

From my reading of the evidence in jurisdictions that had introduced assisted suicide and euthanasia legislation the suicide rate across the population at large in those jurisdictions has generally risen. This in my view is a terrible but a foreseen tragedy. Our laws speak volumes about what we, as a society, think about the value of human life. We must never propose or pass laws that devalue human life.

In conclusion, once again thank you for the opportunity to appear before the committee today and I am happy to answer any questions that any committee members may have.

MRS DUNNE: Thank you for being present today. I think you were in the gallery during at least part of the evidence of the previous witnesses.

Mr Donnelly: I was, yes.

MRS DUNNE: On one occasion a previous witness referred to some research from someone at King's College in London who concluded that, in looking at jurisdictions where voluntary assisted dying, state-checked, sanctioned dying, is implemented there was a fairly bald statement—it may have been qualified in the text—that there is no slippery slope. From your research and the work that you have done, would you agree with that?

Mr Donnelly: Thank you for the question. Can I first of all acknowledge that I am not familiar with the specific research that was referred to by the witness. I cannot comment on the content of that. The issue of the slippery slope is a contested matter—there is no question about that—in this debate with respect to euthanasia and assisted suicide. It was contested heavily as an issue of debate when we had our two debates in the New South Wales Legislative Council.

One school of thought is that one passes a piece of legislation and that is it and therefore the jurisdiction has that and we will work with that. The legislation obviously will have to pass through the legislature again if it is to become more liberalised. That is the argument. The other side of the argument is that once it is in and in place it is just inevitable that more liberal or greater licence will be introduced into the legislation to facilitate the greater ease of access to euthanasia or assisted suicide.

I think the fair answer is that there is no doubt that in some jurisdictions overseas—and I will have to take the details on notice—very clearly legislation has been introduced in the past and then there have been subsequent amendments to legislation or reforms to legislation down the track. I must say that is what greatly concerns me. I have seen that evidence from overseas examples and I just take the view—and I formed this by thinking about it and looking at the evidence from overseas—that once one steps over what one might call a Rubicon or a line and through legislation essentially condones what is assisted suicide or euthanasia, once you have actually passed over that point, I think the arguments are relatively easy to persuade legislators to make it a more liberal piece of legislation in due course. How quickly it might be liberalised will depend on the pressures within the polity of that particular jurisdiction. But I think once you have crossed the threshold it is a case of moving it forward from there.

I might say the other thing that struck me—and I must confess I acknowledge this and, in some sense, congratulate them on their frankness—is that a number of the proponents of euthanasia and assisted suicide in New South Wales in their submissions, but more importantly I think coming through via the members of the Legislative Council that gave evidence, said very clearly that the most important thing is to get a bill up in some form, in whatever form. That is what has got to be achieved; that is the most important priority. And we then move forward from that point.

It is very clear in the minds of, shall we say, the strategists behind trying to achieve euthanasia—at that sort of strategic organising level—that getting a bill in place or getting a bill passed through the legislature, a piece of legislation in place, is the first critical step and then we can build from there. And there is no secret about that. It is quite openly canvassed and argued as a strategy by the proponents of euthanasia and assisted suicide.

MRS DUNNE: If that is what you see as the motivation, the strategy behind a push for assisted suicide, going back to your initial statement, is it possible to codify a system which guarantees protections? The answer to that is essentially no, because even if you get a good system the first time up it will be weakened down the track, either very soon after or at some stage in the future. There is almost an inexorable weakening of the system?

Mr Donnelly: It would be my submission that I do not believe that one can write in black letter law a piece of legislation that can provide what are complete guarantees and protections. That is the conclusion that I have come to. I accept that others come to different conclusions. But I can only inform myself from my experience. And it has been the two debates in the New South Wales Legislative Council.

But more than that, I must say, the experience of the inquiry into elder abuse—and this was somewhat unexpected because we really were not looking at the issue particularly of end of life matters but the way in which elderly are living out the end of their lives here in Australia, in the second decade of the 21st century—was that we were shocked by the level of ill treatment by what are tragically in many instances children of their elderly parents.

I have made the comment to others—and some agree, and some disagree—that I suspect that where we are with our public discussion and reflections on elder abuse in Australia and where that can lead, and I think this is very apposite to this discussion about end of life matters, where we are on this debate here in Australia today, is probably where we were with domestic violence perhaps 10, 12 or 15 years ago. We are only starting to have the issues really drawn to our attention.

Whilst I did not bring it down here with me because it is like a brick, that Australian Law Reform Commission report, which was commissioned by the commonwealth Attorney-General, has led to a number of initiatives and some research being undertaken, I understand, by the Australian Institute of Family Studies, to really look at this whole area of elder abuse very seriously.

It was the subtlety of the abuse and influence which I found the most frightening. I have to be a bit eccentric about this in this sense—and this is an awful thing to acknowledge—because a number of witnesses who came along and professionals who came along were citing that the value of property was a very real, underlying driver of this. We had mums and dads in their 80s, on the old quarter-acre blocks worth multiple millions of dollars, and there were lots of incentives for the children to perhaps think how we might be able to move things along.

MRS DUNNE: The kids could not get into property.

Mr Donnelly: I know that sounds extremely crude and one would think that is just something that would not happen, but there is evidence of children starting off doing small chores for their infirm parents like doing the shopping and then taking $20 to cover the petrol and saying, “Listen, we can do this a lot easier with the credit card.” And they take the credit card. “I need your pin number.” Then they start draining the ATMs of the money. And it goes on and on. This is abuse that is going on of the elderly.

One can have a different view about the extent of it—and I suppose in some sense we do not know the true extent of it—but it makes me very fearful that a person who is old, frail, infirm, particularly with respect to mental capacity perhaps starting to fail, is in an extremely vulnerable position. With the notion of having a legislative framework in place for euthanasia assisted suicide, I just have a great fear about it.

MS CHEYNE: Sorry that I missed the beginning of your—

Mr Donnelly: That is fine. I understand you are busy.

MS CHEYNE: I note that you talked about how some proponents are quite bold and frank in saying, “Let’s just get some legislation through and then let’s expand it.”

Mr Donnelly: Yes.

MS CHEYNE: Those proponents, would you agree, are not necessarily the lawmakers?

Mr Donnelly: Some are, and some are not. With respect, I note that one of your people who made a submission—I was just flicking through it there—was a law professor at the time a few years ago when I attended a Dying with Dignity conference in Melbourne. She presented, and she made that point very clear to the whole group, “This is what we need to do: get some legislation on the books.” I am happy to send her quote in regard to that.

MS CHEYNE: Please.

Mr Donnelly: You have people who are academics; you have, obviously, political activists—that as important in a pluralist democracy, and people are allowed to do that—and we have the legislators. With the legislators, it would be a pretty daft legislator who would come into a debate and be so bold as to say that so explicitly. But certainly, in my private discussions with them, they have made it very clear. Certainly, in the context, if one reads *Hansard* carefully, in their contributions there is pretty clear intimation that we have to start somewhere so let us start somewhere and build from there.

MS CHEYNE: Even though that has not actually been the case in other jurisdictions?

Mr Donnelly: In some jurisdictions it has. I would have to accept that in some other jurisdictions it may not have, and I have not got before me today a jurisdiction-by-jurisdiction breakdown, but certainly—

MS CHEYNE: I do. ABC Fact Check did an excellent article at the end of last year when Paul Keating said that it would be the start of a slippery slope. I am happy to send this to you.

Mr Donnelly: I have not said that I subscribe to the concept or the notion of a slippery slope.

MS CHEYNE: I am not saying that; I am just giving you the context of this article.

Mr Donnelly: Can I just say that I consider that pretty much a pejorative term these days when used in this debate. I do not think there is a lot of use in using that in this debate, because it has been so tarnished. That would be the first comment I would make. The second comment I would make is that, with the greatest respect to the ABC, I would much prefer the parliamentary library or someone with some particular expertise in the area to do a full analysis than to take something off the ABC website, with the greatest respect.

MS CHEYNE: Sure. That is what we have at the moment in front of us.

Mr Donnelly: What?

MRS DUNNE: That is what you have in front of you.

MS CHEYNE: That is what I have in front of me, but you can google it.

Mr Donnelly: I do not intend to google it, because I will not be relying on an ABC—

MS CHEYNE: Regardless, there have only been two countries that have expanded it, and no US jurisdiction has expanded it. In fact the only US—

Mr Donnelly: I do not accept that position. I do not accept that that is necessarily an accurate reflection of what the position is in every jurisdiction.

MS CHEYNE: Okay.

MS LE COUTEUR: Do you have some other information about that?

Mr Donnelly: No. I have not come today prepared with a jurisdiction—

MS LE COUTEUR: On notice. You said you do not accept that information, suggesting that you possibly have some other information about it. I am just wondering, if you did, if you could provide it to us. It would certainly be useful.

Mr Donnelly: I have not done a jurisdiction-by-jurisdiction analysis. I can endeavour to find, on notice, some authoritative peer-reviewed research that has done that. I can undertake to do that. If such research has been done, I will provide it to you. But I have to say that I am not sure I am in a position to be able to spend time to do that sort of research.

MS CHEYNE: Of course. To get to the nub of this, you are rejecting that, not because you have seen research to the contrary but because it is from the ABC?

Mr Donnelly: I am rejecting it because I think, on a matter like this, with the gravity of the situation of what we are talking about here, which is assisted suicide and euthanasia, we need to rely on the highest quality of evidence we can bring before a committee like this. I would consider that to be in the category of material like peer-reviewed research. We are talking about academic papers; we are talking about—

MS CHEYNE: Equally, with all due respect, Mr Donnelly, you are also saying that you think that in many jurisdictions it has been expanded. But where is the academic rigour behind what you are saying?

MRS DUNNE: He did not say that.

Mr Donnelly: No, I did not say that. You are putting words in my mouth.

MRS DUNNE: He did not say that.

Mr Donnelly: I did not say that. I did not say that many jurisdictions have. I am aware that some have—that is my general understanding—but I do not have a jurisdiction-by-jurisdiction breakdown. The other thing I might add, since you raise it—and you have raised it; I have not—is that there is nothing stopping those jurisdictions liberalising beyond what they have got using the basis of what they have already.

MS CHEYNE: There is also nothing stopping them making their legislation more strict.

Mr Donnelly: Well, we are waiting.

MS CHEYNE: Vermont did make it more strict.

Mr Donnelly: Who did?

MS CHEYNE: Vermont. I will leave my questions there.

Mr Donnelly: Sure.

MS LE COUTEUR: You spoke about elder abuse and, as you said, it is an existing issue so it is not an issue caused by the possibility of voluntary euthanasia. Regardless of whether you think voluntary euthanasia is a choice people should have, do you think it would be possible to build legislation which at least reduced the possibility of elder abuse? I am not confident you could ever totally eliminate it, but putting aside your obvious distaste for the alternative, do you think it would be possible to have that sort of protection?

Mr Donnelly: I must confess I am not quite sure what the question is. In some sense the issue of elder abuse is a reality in Australia today—it exists. I do not think anyone is denying that; the scale of it is the question. In the context of a society which clearly has for whatever reason—and I am not speculating what that might be—got to the point where it comfortably tolerates and lives with the level of elder abuse that currently exists, it is particularly concerning to me that we would put into place the legislation being debated.

I have seen the material placed before us in the New South Wales inquiry, and there was in-camera evidence. I have seen how easy—and I use that word deliberately—it is to lean on an old person and get them to move towards a particular decision. The decisions we are primarily familiar with are those to do with financial outcomes and money and all that sort of thing. But I do not think one needs to be too creative in their imagination to see that there may possibly be some temptation if large estates and large wills are in play. I have come to the conclusion that I do not think there should be such temptation.

MRS KIKKERT: Mr Donnelly, is there something in particular you would like to talk about that is not in your submission? I see you have a folder with you.

Mr Donnelly: I will just explain it. This is effectively my submission to this inquiry. When I contemplated how best I could make a contribution to this inquiry—I accept this is very much a judgement on my part and I accept that my views on euthanasia are probably pretty clear to you—I thought I would draw out of the evidence from the most recent inquiry in New South Wales the material I believe is the most persuasive for the no case, drawing on as far as I practically could the best advice I could obtain, particularly from practitioners in the field—that is, the palliative care specialists, the GPs, the palliative care nurses and what is in New South Wales an extensive voluntary network of support for palliative care.

One will find in the folder a number of contributions from those sorts of, shall we say, experts. Because of the complexity of this, one is always tempted to try and sum it up with a simple sentence or a simple explanation and say, “There; that does it.” I do not think one can because it is so complex. But some of these specialists did, and they said, “Greg, at the moment we as medical professionals have the default position of do no harm and do what we can to help a person through the dying process through to the end of life and do whatever we humanly can to mitigate if not totally negate their pain.”

The expert doctors said that modern palliative medicine available in Australia today that is properly made available and properly delivered can essentially deal with virtually all pain and manage it. They did not say 100 per cent, they did not say 99.5 per cent, but they said that if they are given the opportunity virtually all pain today can be properly medicated to mitigate the effect of that pain at the end of life for people. They say this is the track we should stay on to try and bring into the community at large the provision of this. At the moment there is clearly not enough of this available in New South Wales and, indeed, around Australia.

The experts said they do not want to go down the track where, in a sense, we flip the system and we have this default position for people to access assisted suicide or euthanasia. Once it has been flipped, one then has a legislative framework which provides the ability for a person to, in effect, commit suicide themselves or be euthanised. They said there is no going back from that once that has been done because that is a legislative framework. They pleaded very strongly in their submissions to the members of the committee to take that into account in their deliberations.

Whether that was a defining point for the members I do not know, but they were very strong in arguing the case that, for whatever reason, in Australia we have held palliative care out there as not being a central element of health care but a bit player on the margins pretty much being given what bit players get—that is, few resources and less support than it deserves. They said if we can bring that in closer to the centre that will address the preponderance of the stated claims and arguments of people dying in pain without sufficient care at the end of life.

THE CHAIR: The committee appreciates you being here today, Mr Donnelly. When available, a proof transcript will be forwarded to you to provide an opportunity to suggest any corrections.

HORNE, MS DIRA

THE CHAIR: Welcome to this afternoon’s hearing. Could you confirm for the record that you understand the privilege implications of the statement?

Ms Horne: Yes, I do.

THE CHAIR: Thank you. Before we get started with the committee’s questions, would you like to make a brief opening statement, noting the very short time frame?

Ms Horne: Just to say that I am representing myself and a friend of mine who is in a nursing home. I have only written a very short submission, but I appreciate being able to speak to that today.

I care for an elderly woman called Marta Fabri, who is in a nursing home. She is 94. Marta, for the last two years, has been bedridden. Her husband passed away two years ago. She came to this country fleeing the war in Hungary at the age of 18 by herself. I guess she has wished to die for many years, for the last two years, and not just since her husband died but because she is lying in a bed and there is no quality of life. She has no family, no children. There is just herself left. She says, “Every morning I wake up and I cry because I am still here.”

I did put in my submission that it is not about the care in the nursing home. If the care was good and if elder abuse did not exist in places, she would still want to go. When you are lying in a bed and you cannot get up and you cannot move—there is no quality of life for her except to watch *Judge Judy* at 3.30. And that wears her out after a little while.

THE CHAIR: I would be yelling at the television, I think, if it was me.

Ms Horne: Marta asked me to come today. She has made a little two-minute video. She would like to speak to this committee herself. I do not know how I can play this, but she would like to address you all today. She is very passionate about the issue. It is on my iPhone. I could bring it up and you could listen to Marta.

THE CHAIR: Whilst we are talking to you, we might get some advice from Hansard as to how that might work. We are very keen to hear it and be privy to that, but I want to make sure that it is captured correctly and those sorts of things.

Ms Horne: Sure.

THE CHAIR: Whilst we are doing this, I might ask Andrew to seek some advice on that.

Ms Horne: Okay. It is only because she cannot get out of bed to come here.

THE CHAIR: Yes.

MS CHEYNE: Yes, fair enough.

Ms Horne: She would be here herself, speaking in her own words, if she could. I am actually passionate about this issue. I understand the complexities, and it is not an easy decision for any of you to come to or easy to work through those complexities. It is a complex situation. But there are times where people are very clear. Marta is absolutely clear.

The last person spoke about quality of life and pain-free deaths. That does not exist for many. My father passed away four years ago and had the most horrendous death I have ever experienced. And that was with palliative care. That was not good. He had faith; he was a Catholic man. When we talked about even palliative care, he thought it was euthanasia. For him, it would not have been an option, but certainly for my mum and myself—I would not want to go through death like that. I think we do have choices.

So I guess I support voluntary assisted dying in certain circumstances, but Marta wants me to say that she does not wish to live anymore. She is absolutely clear about that.

THE CHAIR: By the sounds of things, Marta is still completely mentally compos?

Ms Horne: Very mentally competent. I mean, she is as clever as. Her story is very interesting. She had to flee the war. When Russia invaded Hungary, they went to Austria. At the age of 16, they were displaced people and were told to go back to their country. Marta could not go back to her country, because she would have been sent to Siberia to work in labour camps, so her parents left her in Austria as a displaced person. She smuggled aspirins from Germany into Austria for a number of years, making her money that way, and was given $2 by an American soldier to get on a plane to Darwin, which she did. She came to Darwin in—

THE CHAIR: Wow.

Ms Horne: Her story is amazing. Then she made her way down to the Snowy Mountains scheme, where she worked as a waitress and met her husband, another Hungarian. They have worked all their lives. Yesterday she said, “This is worse than war. My situation is worse than war.”

For her to just spend every day lying down, having to be lifted in huge lifters, there is no dignity to her life. There is absolutely none. She cannot toilet herself. She has a weak heart. She has asked her doctor to help her die; he cannot do that. She has asked me; I cannot do that. She asks everyone, repeatedly: “Bring me a knife. Bring me something.” I have said, “I cannot do that, Marta.” She is absolutely adamant that there is nothing for her to live for. She is lying there waiting every day to pass away. I think she will go for many years to come, because she is actually not particularly sick. She is frail, and her heart is frail, but she is not—

THE CHAIR: She is 94.

Ms Horne: She has a weak heart, but she is not using that. She says, “I am not even pumping my heart. I cannot get out of bed and run down the corridor.”

THE CHAIR: I think we might have it as a bit of a free-flowing discussion, but Mrs Dunne and others, feel free just to jump on in.

MRS DUNNE: I am right.

THE CHAIR: We do not have very much time, and if we stop for everyone—

Ms Horne: It is just that Marta wanted me to come here today.

THE CHAIR: At the end, we will get you to play it, but then we will probably get you to email it to the committee secretariat.

Ms Horne: I am ready to play that now. I might have to bring it up a bit closer.

THE CHAIR: Ms Le Couteur?

MS LE COUTEUR: My only comment is that when I read your submission I thought you talked about her treatment being really poor.

Ms Horne: Yes.

MS LE COUTEUR: And that that was going to be a major point as to why she wished to—

Ms Horne: No.

MS LE COUTEUR: But it is not? My personal experiences with very poor treatment in nursing homes—

Ms Horne: Yes.

MS LE COUTEUR: You are basically saying that regardless, even if we managed to somehow fix up the nursing home system, she would still not want to be here.

Ms Horne: I think I put that in my submission: even if her care was adequate at a minimum level, it is not the issue. It is not the care; it is lying in bed all day.

MS LE COUTEUR: Yes. You do have that as well.

Ms Horne: Yes.

MS CHEYNE: What would a good death have looked like for her?

Ms Horne: For Marta?

MS CHEYNE: Or what would it look like currently, although maybe that ship has sailed?

Ms Horne: I think she would just like to go to sleep and not wake up. That is it for her. She does not experience lots of pain. There is shoulder pain and there are aches and pains, but she is not a person in chronic pain. There is just no life.

MS CHEYNE: A lot of people today have used the term “tired of life”. Would that be how you would characterise it?

Ms Horne: Yes.

MRS DUNNE: Is there any way back from that that you see? In your general experience, when you see people who are in that situation which could possibly be described as “tired of life”, is there any way of remedying that so that they find more satisfaction in daily life?

Ms Horne: I am not sure what satisfaction one could find just lying in a bed. If she could get out—the last time I took her out was over 18 months ago, so she does not even leave her room. So I think no, not for her.

MRS KIKKERT: Is that due to her medical condition or is that because she just does not want to?

Ms Horne: She cannot walk and she cannot move. There is no way to lift her or move her out without a whole lot of lifters and machinery. The loss of dignity in that, for her to be lifted out of bed to go to the bathroom every day, is horrendous for her. It is quite a traumatic experience.

MRS KIKKERT: Yes.

THE CHAIR: And to be bathed, I would imagine.

Ms Horne: Yes.

MRS KIKKERT: The poor situation that she was in, as you described it in your submission—in relation to power of attorney, did you try to address it with the correct authorities?

Ms Horne: I actually work in the community and have a lot to do with aged care. I have also managed nursing homes in a prior role. You try to address things, and there is payback.

MRS KIKKERT: What do you mean by “payback”?

Ms Horne: You raise issues but conditions get worse.

MS LE COUTEUR: Yes.

MRS KIKKERT: Is that right?

Ms Horne: That is right.

MS LE COUTEUR: Yes.

MRS KIKKERT: I am just asking because my mum works at a nursing home, and every time she has an issue it gets improved.

Ms Horne: Well—

MRS KIKKERT: It is good to know.

Ms Horne: There might be some adequate nursing homes in the ACT, but if you do raise issues, things get worse for elderly people. There is a fear. I have certainly raised issues, and I am recording and documenting. I have made sound recordings; I am recording all the issues, but I am waiting for Marta to pass away.

THE CHAIR: So that she is not negatively impacted?

Ms Horne: Yes.

THE CHAIR: We have heard that palliative care is probably—

Ms Horne: Inadequate.

THE CHAIR: Not well used, not greatly utilised in many nursing homes. Would you agree with that statement?

Ms Horne: Yes.

THE CHAIR: That may not be the exactly correct terminology; I am trying to think of words.

Ms Horne: I think that when you are close to the end of life, it can be utilised and kicked in, but Marta is not at that point.

THE CHAIR: No.

Ms Horne: She is not at that point. She is just lying in a bed. Her mind is sharp. Her body is not failing her. While she has a weak heart and she cannot move, she is not what I would call someone who is very ill.

THE CHAIR: She is not terminal.

Ms Horne: No. She is just old, she is tired and she has had enough.

MS CHEYNE: Kind of similar to the Dr Goodall case that was in the media.

Ms Horne: Yes, exactly. If Marta could get on a plane and go to Switzerland tomorrow, she would be on it. It is that “I am tired of life”. She would be on that plane.

The only recourse you have to the commonwealth aged care complaint hotline is that you have to give specific details, and once you give specific details, it comes back on the residents who live in the nursing home. It is not a matter of just saying that you have concerns about X, Y and Z. They cannot go in and do a check until you give names and details—unless they receive enough.

MRS DUNNE: What you have described is a system failure. It is not that the system has failed Marta.

Ms Horne: No.

MRS DUNNE: It is a system failure.

Ms Horne: It is in aged care. If Marta was still living in her own home—she stayed in her own home for as long as possible—she would still be feeling the same way. This is not about the nursing home; I need to be really clear. This is about her.

THE CHAIR: This is her—

Ms Horne: While conditions are not optimal, this is not about her being in a nursing home; this is about where she is right now in her life. She could be home in bed.

THE CHAIR: How long has she been in the nursing home?

Ms Horne: Two years.

THE CHAIR: And you said that although this has been something she has been saying for a good two years, she has probably felt that way for a little bit longer?

Ms Horne: Yes, but more so for the last year, particularly since she has been bedridden and cannot walk. She was very active: she was a gardener; she went to the pool every day. She had a quality of life that no longer exists.

THE CHAIR: Okay.

Ms Horne: On your question, Vicki, I am not sure what could improve that quality of life, because I cannot even take her out. There is no way to—

MS CHEYNE: And there is no likelihood of improvement?

Ms Horne: No.

MRS DUNNE: There is no likelihood of improving her physical condition?

Ms Horne: No.

MRS DUNNE: But you also do not seem very hopeful that you will be able to improve her outlook on life?

Ms Horne: No.

THE CHAIR: And there is no end in sight?

Ms Horne: No.

MS CHEYNE: Ms Horne, I should declare for the record that I have known you for plenty of years, which is probably the same for most members of this committee. As a power of attorney, do you have thoughts about whether someone should be able to authorise the power of attorney to request voluntary assisted dying for them if certain conditions were met?

Ms Horne: That is a really hard question. I think not. I would not want to make that decision. I think it would have to come from Marta. People need to be really clear. As a power of attorney, I would not want that responsibility.

MS CHEYNE: What if she had something like a pre-approval?

Ms Horne: Possibly. I mean, she has a care plan—

MS CHEYNE: Yes.

Ms Horne: and everything that she wants. We drafted her direct care plan. She is no longer on any medication. She does not want any intervention; so I understand that.

THE CHAIR: If she was to have a stroke tomorrow, for example, and she could no longer speak—

Ms Horne: Yes.

THE CHAIR: and she would be unable to write—

Ms Horne: Yes.

THE CHAIR: but you know that emotionally and mentally—mentally she possibly is still there—

Ms Horne: Yes.

THE CHAIR: Would you see that as your role, as having power of attorney, to make her views known?

Ms Horne: Yes, I guess this is where the complexities come in. The last speaker mentioned this. I think it is not as easy. I could say yes, that I would be comfortable, but I think that that then becomes that complexity that the last speaker actually spoke about in terms of elder abuse. I think there would have to be more than just me making that decision.

THE CHAIR: Sorry, Ms Cheyne, I did not mean to cut in on you.

Ms Horne: Thank you for the hard question.

MS CHEYNE: Yes, it is hard, and I think you are the first person we have had who has an active power of attorney. I think it is good to have on the record the views of someone who is in that position—

Ms Horne: Yes.

MS CHEYNE: to have your views about how you would feel—

Ms Horne: Yes, I would have to really—yes, it was quite a difficult question, I think.

THE CHAIR: Sorry.

Ms Horne: No, it is a good question. It is a big responsibility. I am thinking whether I really want to make that decision even though I am very clear about her views.

MS CHEYNE: I guess the pre-approval is more of a conversation that we were having with witnesses last week. Basically, if they had met X, Y and Z conditions, and if then they were incapacitated to some point but you knew those conditions were met, and they already had that approval, that would perhaps make someone a little more comfortable in exercising that decision.

Ms Horne: Yes, and I am quite comfortable exercising it if she did have a heart attack and had to go to hospital. I am quite comfortable about what I know she wants to have happen, but I think maybe that is just the next step.

THE CHAIR: I note the time.

MS CHEYNE: Shall we try and play this recording?

Ms Horne: Yes.

THE CHAIR: Please.

MS CHEYNE: You might even be able to play it into the microphone.

THE CHAIR: I think that is the idea. Could you also email it?

Ms Horne: Yes, I can. It is only two minutes.

MRS KIKKERT: What is her name?

Ms Horne: Marta Fabri.

A recording was then played—

> **Ms Fabri**: Hello. My name is Marta Fabri. I am over 94 and I am a bedridden customer in the old home for the last nearly one year. I am very, very upset that there is no euthanasia, because every morning that I get up in the morning I am disappointed that I am still alive. Every day, the same procedure: to take me to the bathroom. It is terrifying for me.
>
> I asked my doctor about euthanasia or to help me, but naturally he had to refuse. I am very much for it, that euthanasia should be brought in, because this is just

> suffering. That is all it is. It is demeaning to look after me. I am sorry; my English is not very good. I would like to include that I was always very active in my life. I never was bedridden. Now it is unbearable for me.
>
> Why should I be here, lying in bed and waiting till I die? I am dreading how long it could go on for—two years like that? It is a nightmare for me.
>
> That is all that I can tell. With my husband, I looked after him when he was here. That kept me going. Now at least he does not see how I am. It would hurt him terribly to see me like that. I am just very much for the euthanasia.

Ms Horne: Thank you for allowing me to play that for Marta.

THE CHAIR: Thank you. Just before you depart, Ms Horne, when available, a proof transcript will be provided to you for an opportunity to check the transcript and to suggest any corrections that may be required.

Ms Horne: Thank you.

BURT, DR PAUL

THE CHAIR: Welcome, Dr Burt. Can you confirm for the record that you understand the privilege implications of the statement in front of you?

Dr Burt: Yes, I do.

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

Dr Burt: Certainly. I am appearing as a private person; I happen to be an anaesthetist. Thank you for giving me this opportunity. I have already prepared a letter which I presume you have. I will be talking to either points in that letter or some additional things, and I am open to questions you might have to put to me.

One thing I did not say in the letter, perhaps because it is a little more personal, is that my mother is quite elderly. She is now 90 and she is getting quite decrepit. She lives in an independent living facility in a nursing home; she lives in her own cottage. She has six children, most of whom are in Canberra so she gets a lot of support. She does not want to go to a nursing home but she is getting quite debilitated. She has cardiac failure, a bit of kidney failure and she has very poor circulation in her legs which causes her a lot of pain and for which she has had bits and pieces of surgery.

She has to put up with quite a bit of discomfort and disability even though she is living in her own home with support. She will constantly say to the children when we visit, "I never expected it to be like this. I don't know why I'm like this. I hope this doesn't have to go on for too long." We try and do what we can to support her both emotionally and physically. She does not drive anymore and cannot really even walk to the shops and is really housebound. She is another example of a person of advanced years who is chronically unwell and deteriorating.

Most of the time her mental function is fairly good but her hearing is impaired. She suffers periods of confusion episodically which sometimes stimulate a visit from one of the children—"What's going on? Remember you're supposed to be getting X, Y, Z today"—but she has not got to the point where she cannot live in her own home. However, all of us are very aware of the deteriorating condition she is experiencing and on more or less a daily basis have opportunities to reflect on how this might affect ourselves.

Even though in the submission I put forward I described a lot of things I had experiences of as a medical practitioner of some years, what I have just talked about is more of a personal thing that to some extent shows up some of the limitations of medicine in the modern world. And I am having this put before me on a daily basis, more or less. Nevertheless I am still opposed to the idea of euthanasia, assisted suicide, as a legal change for the reasons I put forward in the letter.

It is difficult to put up with the situation such as my mother experiences. Mind you, it requires constant daily interaction and she does spark up when people are there. For those people who do not have people to visit them, I understand the depth of their loneliness and suffering would be greater. People talk about suffering in terms of pain. Pain is a form of suffering, but there are other forms of suffering which are quite diverse. And suffering is not just a question of how long it goes on for; it is duration, it is diversity and it is depth. I am not trying to oversimplify the issues that beset people in the modern world. “There’s a medical solution.” Well, maybe there is not.

MRS DUNNE: Thank you for your submission and your thoughtful insights and your continued insight today. We have received a lot of evidence about the failures of coverage in palliative care. It is not that the palliative care we have is bad but that there is not enough of it. From your experience in practice in the ACT, where do you see the gaps in palliative care? Do you see there are occasions from your experience where palliative care has not been there at the right time or early enough? Would you like to comment in that space?

Dr Burt: Firstly, I am not a palliative care specialist.

MRS DUNNE: I understand that.

Dr Burt: I am an anaesthetist, and even though I do not practice in intensive care at the moment I still keep my qualification up and have done quite a bit in the private sector, particularly in years gone by. What I know of palliative care is essentially from either my hospital work or what I hear of what goes on at the hospice. In terms of hospital work my contact with palliative care is quite limited and usually through the pain service in my rotational work. As I indicated in the letter, that is not a daily thing; it is more once a fortnight or once a month.

In the hospital environment where somebody is already in a bed in a room being treated usually by some other speciality—it might be haematology or vascular surgery or oncology—it is those specialities that principally have charge of the patients that we might see as consultants. So it is not easy for me to make any kind of criticism or comment about limitations in palliative care in my experience because people who are largely looking after those patients are, say, oncologists and they interface with palliative care people independent of us. In other words, if there are shortcomings they are not things that I see directly.

THE CHAIR: You said you keep your qualifications up.

Dr Burt: Yes.

THE CHAIR: Do you still practise, for want of better terminology? Are you still an anaesthetist?

Dr Burt: I am an anaesthetist. There are formal specialist qualifications in all sorts of areas in medicine—one is anaesthesia and one is intensive care. There is the qualification awarded by the specialist college and then there is the clinical practice which you may do with a greater or lesser degree of frequency. There are people who have both qualifications like anaesthesia and intensive care, and some might do two days a week of intensive care and two days a week of anaesthesia. I just do four days a week of anaesthesia these days, but I interact a lot with my intensive care colleagues.

THE CHAIR: Thank you for the clarification.

MS CHEYNE: I note your comments in your submission, and even in your reflection today, that you do not support such a scheme of assisted dying. Equally, in your submission you note that of the many deaths that you have been exposed to through various different capacities in your life, among the worst, the ones that have had the greatest ongoing impact, have been suicides. How do we reconcile the situation where people are in such unbearable pain or are so scared about the loss of their dignity that in the absence of an assisted dying scheme, they are taking their lives anyway?

Dr Burt: I know some people who have managed to get themselves an appropriate supply of whatever medication they think will do the job and keep it in the top drawer, so to speak, for an occasion. I guess some people might be in that position. I referred to my mother before. She does need quite a lot of support in terms of managing some of these issues of pain. At her age, in her state of disability and with the kind of pain that she suffers from, there are no adequate drugs really to manage that.

MS CHEYNE: There are none?

Dr Burt: There could be drugs that she would be given that would seriously disturb her mentation or put her in a state of considerable confusion or disorientation. So although there has been a bit of playing around with trying to use those, their effects seemed to be sufficiently negative to have had them withdrawn by her GP.

I think there are some people who do have some forms of pain that are fairly hard to relieve or improve much. They are not usually in hospital. In hospital you can often give people intravenous medication and other things that are quite helpful. If people are dying, the regime of opiates or whatever they are on might be stepped up to the point that they become relatively drowsy. But in a domestic environment these things are not so readily accessible unless one is definitely dying.

I do think there are people who have some form of pain that is hard to manage. The only alternative for them, apart from ordinary human comfort and what one can do to try and use some sort of psychological support, is really endurance, I daresay, in the absence of actually giving a lethal dose of something.

MS CHEYNE: An example that sticks in my mind, and Ms Le Couteur might recall this, is one that Professor Brian Owler refers to on occasion, a case in Victoria where a man in unbearable pain, not in a good way, said to his family, “You are by my side all the time. Why don’t you take yourselves away for a nice weekend? Relax a bit and I’ll be here when you get back.” The case was that he did not want to implicate them in his suicide. He had been stockpiling his medicine. He did decide to commit suicide while his family was not there. Those are the cases for me. And just reading your own evidence, suicide is where the lasting impact really is. How do we otherwise avoid that, those situations where people are taking their own lives, leaving this guilt for their families and dying very lonely deaths?

Dr Burt: I do not necessarily propose to have all the answers, I have to say. I do not have all the answers either in a general way or in a particular way for individuals. I am not proposing to put a perfect solution, you understand. I do think that some of these things are problems what we are left with in society. I am not denying there is a problem; I am just suggesting that the proposed solution is not a good one.

I also have to say, and this is probably the time to say this, that I have a religious view of life. I am aware of the fact that many people do not. This is a pluralist society; I understand all that. But I also think that there are many people who claim to be religious and, quite frankly, I would rather they did not make the claim. They certainly give the idea of religion a bad name. An obvious case in point is the recent problems of sexual abuse so prominent in the royal commission. But that is only one instance.

I do think that religion is a very strange thing. I think there are people who can claim to be atheists who are really religious, and there are people who can claim to be religious who are effectively anti-religious. With what people say they are or what people say they believe, I do not know how much you can trust a lot of that stuff.

But one of the things that strikes me in the modern world is that I think we almost need a kind of secular religion, if you do not think that is too much of a contradiction in terms. By that I mean that death is a phenomenon that we will all face. You can say you are not religious, and that does not at all bother me, but what is going to happen once one dies one does not know. I have alluded to this in the letter. It does not matter whether you think you are religious or not; you have no idea what is going to happen.

One of the reasons why I put some of the quotations in that letter that I did—from Shakespeare, for example—is that I do not think Shakespeare mentions God in any of his plays. He mentions the gods at times in a sort of somewhat pagan traditional fashion, but I do not think he ever mentions God. And when he is reflecting on suicide in that famous soliloquy in *Hamlet*, he does not say anything about God or the afterlife; he just asks the question: what happens? He has a very negative spin on it, of course: life is a bitch and then you die, that sort of thing. At the same time, JM Barrie in *Peter Pan* says, “Dying would be a great adventure, don’t you think?” He does it again. There is no mention of religion. It is just the question put.

I think death presents this question to people. What is existence? What is human existence? These are philosophical questions. To some extent, it seems to me that the modern world has gone away from asking general philosophical questions that do not have a clear answer. I think it is a question that confronts us all. The issue is: do we survive death? Is existence permanent and is death just a stage in that existence? Or if we do survive death, does it somehow matter how we lived and died? I think those are really fundamental questions.

The issue of suffering then interfaces with this. Is the suffering that we experience in life and at the end of our lives of some material value in terms of what kind of existence we experience subsequent to dying, assuming we have one? That is the real issue that I think is important here. Sure, the suffering is terrible that some people endure, but could there be some worse form of suffering? That is the question that Shakespeare asked in *Hamlet*. Or could there be some form of greater, more valuable existence that we are yet to experience? And does that depend on the kind of life we have lived?

MS CHEYNE: Shouldn’t it be a person’s choice if they want to suffer or if they want to roll the dice and say, “Oh, well, maybe in the next life I will suffer more, but I will take my chances"?

Dr Burt: I see that point, and I am not making the decisions or handing out the guernseys or anything. It is not up to me in any case. What I am simply suggesting here is that it is such a big decision to decide to go that route and take that gamble that I think it is too important a gamble to take, as I see it, not just for me but for others.

In some funny way, I regard this as a bit like the issue of climate change. People can say there is no climate change or "We are the Liberal Party. We are going to decide on a democratic basis whether it exists." People have no idea. Are we going to take the gamble on this? "Oh, well, somebody else will pay the bill." Will they? It is an issue of controversy. People argue about responsibility. People argue about consequences. People deny it. But it is not a matter that is decidable by a democratic process. In some sense I see this as being a scientific analogy to this particular problem.

MS CHEYNE: I note the time. Ms Le Couteur and Mrs Kikkert?

MRS KIKKERT: I can put my question on notice.

MS LE COUTEUR: I would like to ask this. We have had a lot of evidence that there is not enough palliative care in the system.

Dr Burt: Right.

MS LE COUTEUR: Given that you are someone who is actually involved in the system as a clinician, would you have any ideas about where would be the best places, how we could best get more palliative care in?

Dr Burt: This is a specialist medical training issue, I would see. There would be some people who might have skills that they could be interested in transitioning to that area. There is a woman called Maria Cigolini who is the director of palliative care at Prince Alfred in Sydney. I talked to her a little while ago about how easy it would be for an anaesthetist to move across to that. A lot of this training is very formalised now; there is no shortcut route. But that is one way of getting people with the skills, in drug management perhaps, into that area.

THE CHAIR: Thank you so much for appearing today. When available, a proof transcript will be provided to you to allow you to have the opportunity to check the transcript and suggest any corrections, should they be required.

Dr Burt: Thank you for giving me the opportunity.

GIBBONS, DR SIOBHAN

THE CHAIR: Dr Gibbons, could you confirm for the record that you understand the privilege implications of the statement there on the table?

Dr Gibbons: Yes, I do.

THE CHAIR: Are you happy if we get straight to questions, Dr Gibbons?

Dr Gibbons: I have just a small statement to make. I am a veterinarian. I have worked in a private veterinary small animal practice for more than 10 years. I would like to note for the record that I am currently an Australian public servant, but I am here today in an individual capacity and I am expressing my own views. I want to thank the committee for giving me this opportunity to speak on this matter. I think that the discussions that are taking place here are very important.

I want to add two things to my submission. I stated in my submission that I think the Victorian model would be a good model for the ACT, with a couple of concerns that I added about time frames around implementing when people have applied. But, having heard what a lot of other groups have said during the committee hearings, I would like to say that I do actually agree that the Victorian model may be too limited in what qualifies a person to be eligible. I would defer to those experts as to where that sits.

The only other thing I would like to add to my statement is that I appreciate that this is a highly complex and emotive issue for many people, and how a person feels about voluntary assisted dying and euthanasia depends largely on their personal values and on their own experiences. But I think it is really important, and I know a lot of people have already said this, that we provide people with a choice so that they have the right to make a decision and make a choice about their own lives.

THE CHAIR: Thank you. We will work this as a free-flowing discussion, to give everyone an opportunity to ask questions, particularly Ms Le Couteur and Mrs Kikkert. They have largely been last on the list.

MRS KIKKERT: I just have a quick one. Can you confirm that while the poison Nembutal has been approved for use by vets such as yourself, it is not legal to use it on humans?

Dr Gibbons: The drug that veterinarians use is actually pentobarbital, which is the same. It is essentially a barbiturate. I am not a human medical practitioner, but so far as I am aware it is not legal for use in humans currently. But I am not a medical professional. Obviously it is legal to use it in animals for the purposes of euthanasia.

MRS KIKKERT: How long does it take to be effective on an animal? Is it quite instant? Is it a couple of minutes, a couple of hours?

Dr Gibbons: No. It depends on the way that it is administered, but essentially the most common way that it is administered is intravenously for animals, and it is very quick. It tends to take 10 to 30 seconds, generally. It is very quick; it is very peaceful.

The drug is actually an anaesthetic. It was used as an anaesthetic agent a long time ago, but it is used at higher doses to perform euthanasia in animals. Because of its anaesthetic quality, what it essentially does is—if you have had an anaesthetic yourself—render the patient unconscious and then depress the respiratory system. So you stop breathing; it renders you into what we call respiratory arrest. You stop breathing then, subsequent to that, the patient's heart stops beating. It is very, very peaceful; it is very, very quick.

MRS KIKKERT: That would be an ideal scenario for a human being to die, but it is my understanding that, for humans who have opted for euthanasia in America, it tends to last for about nine hours before they finally pass. Do you consider that a fast way of dying?

Dr Gibbons: I am not familiar with how the drug works in humans. My background being veterinary medicine, I can only comment on how it works in animals. I am not familiar with how the drug is being administered to people in that setting. I would suspect that it is not being administered intravenously in that setting; it is probably being administered as an oral medication, I would presume.

If you are being administered a drug where it is going to take nine hours for you to pass away, the question of whether or not that is humane depends on how you are passing away. If the person goes to sleep and then gradually, over the course of the next nine hours, their respiration slows, they stop breathing and then their heart stops, that is still a peaceful death; it is just a long period of time.

It is about managing the expectations of those that are around, watching the person. If that is something they are using and you have family members who are going to sit and watch and be with you and hold your hand, I would expect that the medical professionals would have said to the people, "This is the way this tends to work. He will take the drug. This is what you will expect to see. This is how long it can take."

Managing those expectations is what makes it peaceful as well. If you think someone is going to die quickly, and then nine hours later they are still alive, that is very traumatic for the family to watch. It is about making sure they understand what to expect and making sure that the person experiencing it is not in pain, is not scared, and is comfortable.

MS CHEYNE: I have a follow-on from that, Dr Gibbons. For the record, I know you in a personal capacity. Some of the evidence we have heard, particularly today and maybe last week—I do not know where we are any more—has indicated some concerns about when the drug is administered, that it has actually ended up causing a patient extreme pain in a few circumstances. I think the Australian Christian Lobby gave the example this morning that in about three per cent of cases things go wrong. In your experience, again noting the totally different species, is that a risk?

Dr Gibbons: I guess it depends on your definition of "things going wrong". I did not actually see that group, so I do not know exactly what they said or what stats they looked at. Any medication being given intravenously has the chance to cause some discomfort if you have irritation to your veins. Humans can tell you, "I have had antibiotics given to me intravenously and it was uncomfortable." I imagine that for some people, anything being given intravenously, if you have irritated veins, could cause the same sort of discomfort. There are things that you can do to help minimise that.

In my patients, again noting that they are animals, there are things that “go wrong”. The “going wrong”, in my view, is generally more if, in rare cases, patients can move or twitch after they have lost consciousness. After they have stopped breathing, they can suddenly gasp. That can happen when people or animals pass away naturally as well. One of my patients had more severe tremors after the drug was given; I guess that could be viewed as something going wrong in the process of giving the anaesthetic. However, my patients were all unconscious at the point that those things occurred; they were not suffering. These are just natural things that the body does as you pass away, regardless.

Again, it is about managing expectations: in my case, explaining to the pet owners or the family that in rare cases they may see these things occur as the drug is administered. It means that if they are one of the rare cases where this does occur as the drug is administered, the family is not distressed, because they know that we have already said that this is something that might happen, and they understand, then, that it is something else occurring as a result of the process of passing away. That makes them more comfortable. And, most importantly, it is not that the patient is experiencing any pain or suffering, because they are already unconscious and they are already asleep.

I think we have to keep our eye on the purpose of what we are trying to achieve: a comfortable, peaceful death for somebody—in my case, my patients. That is still being achieved. I do not perceive cases where that happens as anything going wrong. If you talk to people who have actually witnessed people dying, all kinds of unpleasant things can be witnessed as somebody dies without a drug being administered to them. Does that answer your question?

MS CHEYNE: It does.

THE CHAIR: I have had a very privileged life; growing up in Canberra we got to know our vet extremely well. I got to experience working very closely with our vets, one of whom has passed away, Richard Chapman. We were very close to Richard. During that time I had many animals that I was allowed to and wanted to inject, under veterinary supervision, to give the phenobarbital to put my animals to sleep.

One such case was a horse we had to put down. She was a fighter, and it took an awful lot more of the drug than we all assumed it would. Bill Ryan was my vet in those days. The horse fought, and it was very distressing for me. Even knowing she had to go and even knowing this was the most humane thing I could possibly do and even having had explained all the things you have just explained today, it is still very hard. She had cancer. This horse was extremely fit, extremely fast, extremely fat by nature—she was a Welsh mountain cross Australian stock horse, so she was a round horse—so to see her rib bones and her wither appear, I knew the only choice was to be humane and end her life. I have not regretted that. I was eleven years old. The *Canberra Times* made it a front page. It was really distressing, the whole process that happened afterwards.

The only humane thing I got out of all of that was exactly what you said—my vet sat me down and explained everything that may or may not go wrong and I was prepared. Technically speaking, that could have been, as you have just said, something that went "wrong", but I did not feel that was the case.

Dr Gibbons: It is very difficult drawing comparisons between animals and people. Horses being very large animals, they require much larger volumes and it is much more difficult to restrain them gently in situations such as this. It is not like you can gently wrap your arms around them and hold onto them. So that makes things a little bit more difficult.

But I think the other thing with animals is that animals do not choose this for themselves. We cannot explain to an animal what we are doing. So they come into a veterinary situation and that is scary for them and they do not understand what we are doing. So where an animal might be struggling against you and trying to get away from you while having a catheter put in and all those sorts of things, that is more specific to veterinary medicine.

I do not think that is something you would experience in this particular scenario because this is a human who is choosing and making the decision that this something they want. You are not going to have them bolting while you are trying to give the injection. You also have the benefit that you will have talked them through what is happening and what to expect, all those sorts of things. It is something they have chosen.

THE CHAIR: And that is the point—it is a choice.

Dr Gibbons: I think that also means you are removing the particular risk that vets face with something going wrong. You will not have that with people because it is the individual's choice to do it. Depending on the model chosen, they are self-administering in some cases anyway.

MS CHEYNE: Dr Gibbons, throughout the hearings so far some people have said they are very concerned that, if a model of assisted dying was introduced, the relationship between the physician and the patient would potentially deteriorate or be compromised. Others have said it would actually improve the relationship because the elephant in the room would be able to be discussed. Where do you stand on that in your experience as a medical practitioner?

Dr Gibbons: I think I commented on this in my submission. I heard this kind of thing thrown around in the media when the Victorian model was being brought in. I find it really offensive that people feel that way. As a veterinarian I treat patients and I euthanise my patients when appropriate. I do not think my capacity to perform my job properly and to give the very, very best of care to my patients is in any way compromised by the fact that, when appropriate, when there are not other options, when my patients are suffering, I also am legally allowed to euthanise my patients.

I do not think my relationship with any of my pets' owners is compromised by the fact that I see them, I treat them and, at the end of their life, I put them down. In fact, most pet owners, in my experience, develop a relationship with the veterinarian as a general practitioner. If you ask them who they would want to euthanise their pet at the end of their life, their choice would usually be to have their veterinarian who has seen their pet and treated their pet and knows their pet to perform the euthanasia at the end because you have that relationship. You have been on the journey with them. You know all of their health concerns. You know what the pet is like. So, using the veterinary model, I absolutely do not think it would compromise people's relationships with their general practitioner. I think it would make it stronger.

MS CHEYNE: We have also heard about pressure from adult children—elder abuse—and pressure put on practitioners. In the case of palliative care nurses it can be: "What can you do? Please do something." Have you been pressured by a pet owner or similar to euthanise a pet where it was inappropriate to do so and, if so, how did you handle that as a medical practitioner?

Dr Gibbons: Veterinary medicine is a bit different in this regard because we are able to euthanise pets for a variety of reasons. Sometimes those reasons are not what veterinarians would prefer; sometimes animals are euthanised where you would never euthanise a person. You may be asked by a pet owner to put down a pet for various reasons at a point where you would never ever consider euthanising a human. In veterinary medicine that decision is a pet owner's decision and it is their right and they will have various reasons for that.

I would only ever try to dissuade a pet owner from that decision if I felt they were the kind of owner who actually wanted to go further with their pet and for whatever reason they felt they could not. That would be something that we would talk through in a lot of detail.

In this instance, for humans, if a robust system is put in place that could not happen because the fact of the matter is—if we look at the Victorian model—it cannot be the family member coming in and saying to the GP, "I think you should be allowing my mother voluntary assisted dying," or "I think you should be euthanising my sick father." The stipulation in the Victorian model is that the patient themselves has to seek it out, through two different practitioners. It has to be something coming solely from the individual. The general practitioner is not allowed to ever raise it as an option themselves; it has to be that the patient goes to the GP and raises it themselves.

I think safeguards can be put in place to ensure that a general practitioner is not being pressured by somebody external—and somebody that it should not be. Fiona May spoke recently about the safeguards and the decision-making. The things she spoke about were really telling to this point. One of the things she and her colleague were saying is that if you know somebody wants something and they have made that clear throughout their life, if they suddenly change their tune and you find their daughter is in their ear, I think you know. So I think there are safeguards in this instance that could be put in place to ensure you are not being pressured by the wrong party.

THE CHAIR: Thank you, Dr Gibbons, for talking to the committee today. When available a proof transcript will be forwarded to you to provide an opportunity to suggest any corrections, if required.

MORTON, MR TIMOTHY

THE CHAIR: I welcome today’s last witness, Mr Morton. Can you confirm for the record that you understand the privilege statement in front of you?

Mr Morton: I do.

THE CHAIR: Thank you. Before we proceed to questions, do you have a brief opening statement you would like to make?

Mr Morton: I do. I am appearing in a personal capacity today. I am a 31-year-old solicitor practising here in the ACT. I have practised my whole career in succession law, that type of space; so these sorts of topics come up quite regularly for me.

I have probably assisted somewhere in the vicinity of 300 to 400 clients over that time with their estate planning. Part of that discussion involves a discussion about their end of life wishes in the form of their enduring powers of attorney. I am quite privileged to be able to assist my clients in putting together their wishes in a clear and hopefully unambiguous way.

The vast majority of those clients wish to ensure that they do not suffer unnecessarily. If I had to put a number on it, I would say that the number of clients that want to include some kind of direction as to their end of life care would be in the order of 70 per cent. They would be saying that they do not want to be kept going.

THE CHAIR: Say that again?

Mr Morton: About 70 per cent; that is just putting a number on it to give an idea of magnitude. They want me to put in a direction that says, “Keep me free from pain and I refuse all other medical treatment.” It is tantamount to ending their lives in those circumstances.

I am particularly passionate about elder abuse. It is an entirely separate note, but, as you have noted, it has been raised here today. I urge the Assembly to look at this closely in the future. It is a big topic.

My submission, of course, presumes the availability of a right to die. I see it as a way to reduce unnecessary suffering. I have drawn on personal examples and examples that I am otherwise aware of in putting together my submission.

I have argued that we should not treat those who lack capacity any differently. We should not treat them as being less worthy of accessing voluntary assisted dying, particularly where they have had the opportunity to express their wishes in the past. To do so limits their agency, limits their ability to interact with the world and the society which they live.

I share the concern of many who appeared before this committee. I have watched many of the submissions online. No doubt, the committee shares those views—that you would need sufficient safeguards if this sort of model were to come into the ACT.

However, I do not share their pessimism that such safeguards cannot be put in place and agreed. If such legislation were constitutionally passed in the ACT, the Assembly would be more than able to put together sufficient safeguards to protect the interests of vulnerable people.

English jurist William Blackstone is famous for his commentaries on the law in England. He talked in the context of criminal law about a maxim that is oft repeated now: it is better that 10 guilty persons escape than one innocent suffer. While that is a different context completely, it does have relevance to what we are talking about here today.

Certainly, any balancing act that is performed needs to favour someone continuing to live if you are unable to discern what their wishes are. But it does not necessarily follow that those that remain unambiguous in their wish to die, should their suffering be too great, should be required to continue to suffer until their lives end naturally. I encourage the committee in that context not to let the perfect be the enemy of the good.

MS LE COUTEUR: I am very interested in issues of capacity, partly on the basis of experience in my family. It was very clear what my mother would have wanted to do but she clearly also had lost capacity. However, I have also observed quite a number of people who have had strokes. How do we have enough safeguards so that people do not end up in a situation because they have made a decision at one point? When you are young and fit and healthy, you may feel that living with some sort of disability or incapacity is not what you want to do. But if you get to that stage, you may feel otherwise. How do we put in safeguards so that people are making a decision they would agree with at the time it was made?

Mr Morton: The same question might very well arise in the context of making a will. The law has developed over a long period of time very clear tests as to what is sufficient testamentary capacity. Solicitors that do not probe and test adequately are going to be the subject of a great deal of criticism.

Certainly, what we are talking about here is much more permanent and harder to rectify—impossible to rectify—if the wrong decision is made. I think the answer to that is that if you have made a power of attorney—this is a very hypothetical scenario—that authorised euthanasia or voluntary assisted dying under particular given circumstances and you have now changed your view, the position would be that you would need to update your power of attorney.

MS LE COUTEUR: I guess the issue arises if you have changed your view but you are now regarded as not being mentally competent. That is the question. Clearly, if you are mentally competent, the power of attorney will not come in anyway because you would be looking after your own affairs.

Mr Morton: That is right. You are talking about a very difficult point. The only thing I can really point to is the paradigm shift that is occurring in this space right now, moving from substitute decision-making to supported decision-making. That is to say, if a person cannot make the full decision themselves but they can make, say, 30 per cent of the decision themselves, the role of the attorney ought not to be to scrap that

30 per cent but to apply the necessary decision-making power to bring him or her up to the 100 per cent.

That is a question for attorneys. Attorneys need to be much more aware that the decisions they are making are not plenary. They are necessarily limited and need to be in the best interests of that person or compliant with their wishes as expressed, say, in the power of attorney or as they are already aware of.

MS LE COUTEUR: We have already talked about elder abuse but that sort of opens that up again. Typically, the attorney is going to be a member of the family. We have heard that that is where most elder abuse happens. I do not know what the answers are, but this is the issue.

Mr Morton: Nor do I. We have heard a lot about the evil adult children and—

MS LE COUTEUR: They are not all evil.

Mr Morton: And they are not. They are not. I want to emphasise that the vast majority that I deal with have no problems. They all get along swimmingly. It is very rare that there is any dispute and it is very rare that the clients will come in saying that they want something that is not in mum or dad’s best interests. They come in saying that they really want to do what is best for mum, that they want to look after mum.

While I think attorneys do not necessarily understand as well as they should what their obligations are and what their duties are, they are generally quite caring and they generally do their best to help their parents. Coming back to your question, it is very hard to regulate, but the ACAT exists. If there is a whiff of a problem, dispute or conflict that is not in mum’s best interests, ACAT can revoke that power of attorney and does.

MRS KIKKERT: Thank you, Mr Morton, for being here today. I refer to point 17 in your written submission. It says:

> I believe that the right to access any voluntary assisted dying scheme should be available to anyone who is suffering from a terminal disease. This should include dementia and other cognitive diseases that permanently impair capacity.

I understand that obviously there are various stages of dementia and cognitive diseases. Are you suggesting that patients with dementia at the early stages have euthanasia?

Mr Morton: In my view, in my experience, the thing that clients are most concerned about when they raise it with me is, for example, the diagnosis of dementia. Personally, I would not want to continue living fairly quickly after a certain point in that diagnosis. That is where the supported decision-making comes in. If someone with an early stage of dementia wants to make that decision, the attorney should be able to supply the necessary supports so that they can make that decision.

MRS KIKKERT: How many clients have you had with dementia?

Mr Morton: In my context they seldom have dementia. By the time I meet them, it would be very difficult for me to assist them if they did have dementia. Having said that, I have had some.

THE CHAIR: If possible, could you expand a little on point 21 of your submission, where you say that—and I know that you mainly deal with elder issues, but I found this very interesting when I read your submission—the scheme should be available to children, either through their parents or through the court. Can you expand a little bit more on that for me?

Mr Morton: I think it is linked necessarily to point 22. The analogy I make there is with statutory wills. Where a person does not have capacity, the court can step in and make a will for that person under those circumstances. But in that context the court is exercising its protective jurisdiction. This is a jurisdiction that is not exercised with any haste. It is exercised very cautiously and after considerable deliberation and discussion. What I am talking about is a situation where a child will inevitably suffer and die, where that is going to happen. The safeguards exist in other areas of law. It seems to me that it would be entirely possible to put sufficient safeguards in in this context as well.

It does not make sense to me that someone under the age of 18—again, back to this supported decision-making—who might be able to make much of the decision with the assistance of the court and input from parents and family might very well make the full decision, but an infant who has terminal cancer that is going to spend months and months screaming in agony cannot. Merely not having capacity, though we should protect these people, does not mean we should protect them so much that we force them to suffer unnecessarily and inevitably towards a death that just did not need to be that painful.

MS CHEYNE: Just on that—and, again, I will declare that I know you in a personal capacity—I think something that is often referred to is how the Belgian model was expanded to include children, on the basis that age is arbitrary in terms of someone’s ability to act competently for themselves. What are your views on that?

Mr Morton: I have met some extremely mature 15-year-olds that could make a whole range of very good decisions, and I have met 40-year-olds who probably should not be able to. I think what we are talking about here is maturity. While they may not appreciate the full ambit of the decision that they are proposing to make, the court and the law should be able to support them in doing that and, if necessary, tell them that they cannot. I am not familiar with the Belgian law, so I cannot comment on that.

MS CHEYNE: Today we have had, remarkably, a lot of people comment about their concerns around elder abuse. However, you are the only one who has commented in support of voluntary assisted dying. I think most people have used elder abuse as a reason not to go down that pathway. Are you able to step us through why that is your position, as someone who actually practices and has legal knowledge in that field, and why you have come to that view? What elements would you like to see in a voluntary assisted dying scheme that would appropriately safeguard against that?

Mr Morton: I guess there is no way of getting around the fact that elder abuse happens, most often financial. The term elder abuse, though, is apt to mislead. It can be anyone that has impaired capacity and is no longer able to make those decisions themselves.

I have one example right now which you would very well term elder abuse of an adult who has early onset dementia and has had significant sums of money removed by the attorney. Mostly it is financial. Obviously, you fix that after it has happened. But the question is this: how do you stop it happening early? I think the answer to that question is going to involve the courts and tribunals. I do not necessarily think that an attorney should be able to just simply make a decision that someone's life is going to end unilaterally.

I think that society, and law, has an interest in ensuring that that decision is being made properly. It might very well be made by short application to the tribunal for some sort of direction. The tribunal has already got the power to give directions to an attorney and, to the extent that that power is not sufficient, it can be expanded upon.

That would be a relatively straightforward process. Of course, in cases where capacity is non-existent—they do not have a power of attorney; I am thinking there about those minors, children—then the process I have proposed there would involve an application to court. This is an expensive process for the family but a necessary one, I think, to protect the rights of the person.

To emphasise, I am not saying that there should be an unmonitored right by an attorney to consent to the ending of someone's life. Certainly the only time I would support it would be in a situation where someone has expressly authorised their attorney to consider that or consent to that if they considered it appropriate.

The form that we have in the ACT for a power of attorney is quite comprehensive. It has undergone a few changes recently. But there is no reason that such a document could not have a standard authorisation for an attorney to make those decisions, under particular circumstances and with guidance from the law as to how that decision ought to be properly made. I think it is entirely appropriate that an application to ACAT be made to approve such a decision.

MS CHEYNE: So, in short, you think the concerns that advocates against the scheme have raised about elder abuse can be appropriately mitigated in almost every circumstance?

Mr Morton: Yes.

MS CHEYNE: Thank you.

THE CHAIR: I know we briefly touched on enduring power of attorney with Ms Le Couteur earlier. I know that enduring power of attorney is slightly different to some of the other—I cannot think of the word that I am looking for—advance care plans and directives. We have heard that advance care directives in particular are quite cumbersome and clinical and may need to be quite clinical. Do you think that there is room to make enduring powers of attorney a little more in plain English, for want of better terminology? I know that they can also be very difficult to understand in some circumstances.

Mr Morton: Yes, I would agree. I would actually argue that it should be that complicated, though. The power you are giving an attorney is just enormous. There is an active discussion in the legal community right now about how we could limit elder abuse. I think this is in the ALRC report. They consider witnessing requirements.

In the ACT all you need to have is a stat dec witness, which is a whole host of people, to witness your signature on a power of attorney and then one other adult witness, which can be anyone. It does not need to be a legal practitioner. It does not need to be any particular person. When you are giving someone that sort of power, I think you need to give them advice as well or there are going to be abuses.

Part of strengthening the law in relation to elder abuse—I would personally advocate for this—is strengthening witnessing requirements and potentially even requiring an attorney accepting an appointment to accept that appointment in front of a lawyer who gives a certificate setting out what their obligations are.

THE CHAIR: In all instances? Not just in the instance of voluntary assisted dying?

Mr Morton: Most certainly in the latter case. But I would advocate in the former case as well, just because of the high incidence that I do see of financial elder abuse. It is very easy to get a document signed.

You mentioned health directives. They are—certainly in my context—of limited use. I have heard them described as not being legal documents as such. Some would say it is a strength. But they are subservient to a power of attorney. If a power of attorney is entered into after a health direction has been made, and that power of attorney has health power in it, then that health direction is effectively revoked. It is subservient in that very real sense to a power of attorney.

The other document that you may or not be aware of is a statement of choices. It is much more detailed and voluminous as to what decisions a patient would like made or not made in relation to their care.

THE CHAIR: If there is a change of mind at some point after an enduring power of attorney is put in place with a lawyer—for argument's sake, the person has asked that no medical interventions occur and there be no life support; whatever the case may be—but the enduring power of attorney does not get updated, the enduring power of attorney still stands, does it not?

Mr Morton: It does. And unless they decide to revoke it—and that is a relatively quick process and—

THE CHAIR: Absolutely. But if that is not done and there is a death—and there has been a change of heart that is known about—the enduring power of attorney still remains the—

Mr Morton: And the overriding principle should be that that person, the attorney, should be making decisions that are consistent with the wishes of the principal, the person that made the power of attorney. If they are able to talk to their loved one and that person said, “Look, although I know I’ve got euthanasia in there, and I know I’m quite poorly right now, but I’d rather keep going at least till Christmas, and see how we are then”—to the extent they are able to express that of course—then that attorney ought to be exercising their powers consistent with their wishes. Again, they should support their decision, not substitute their preferred decision for the principal’s decision. I think there is an education issue there about what attorneys can and cannot do, and when they can and cannot make those decisions.

THE CHAIR: I think we are all questioned out, so I would like to thank you very much, Mr Morton, for giving the committee your time this afternoon.

The committee adjourned at 4.51 pm.