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, 24 MAY 2018

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

By authority of the Legislative Assembly for the Australian Capital Territory

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

WITNESSES

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Amended 20 May 2013

The committee met at 9.32 am.

ARTHUR, MS JEANNE, President, Dying With Dignity ACT

THE CHAIR: Good morning, everyone, and welcome. I declare open this third 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 and are being recorded by Hansard for transcription purposes, as well as being webstreamed and broadcast live.

I remind witnesses of the protections and obligations entailed by parliamentary privilege and draw your attention to the pink privilege statement on the table in front of you. These are important. I welcome today's first witness, Ms Jeanne Arthur. Could you confirm for the record, Ms Arthur, that you have read the pink privilege statement and that you understand the implications of the statement?

Ms Arthur: Yes, I have read it and I understand the implications.

THE CHAIR: Thank you. We will jump straight into it.

Ms Arthur: I thought that I would begin this session, using the five minutes that you have allocated to me, by giving you a bit of my personal background. Our submission was fairly theoretical and I thought that it would give you a bit more context if I did that. I have been involved with Dying With Dignity ACT for 13 years, so I have been engaged in this activity for a big chunk of my life. Voluntary Euthanasia ACT began as a sub-branch of Voluntary Euthanasia New South Wales in the 1980s. I think we have a very strong reason for being here and addressing you today.

I became involved in 2005, when I retired. I had been following the articles that had been written about and reporting on Philip Nitschke's activities and the issues in the Northern Territory with the Rights of the Terminally Ill Bill. So that had already engaged my attention. I retired, and I was starting to think about my death—that this was the big thing that was coming. Being a person who thinks ahead, I wanted to get involved and to take some initiative on this matter.

I had two friends. Helen was one who had motor neurone disease. It took her six years to die. I saw her gradually waste away. This was a very disturbing incident for everyone around her. She was loved by many people. With another friend, Robyn, I began teaching in the 1980s and she hanged herself. We were both connected through our interests in drama and this was a very shocking incident for me. What I realised, as I began working on the issue of dying with dignity, was that both of those bad deaths occurred because of section 17 of the Crimes Act or its equivalent, because Robyn died in New South Wales. I now know, having looked at the law around the country, that the law is much the same everywhere.

I have dedicated myself to looking for ways to show that the Euthanasia Laws Act and section 17 of the Crimes Act are unlawful, wrong and unjust in many ways—from a constitutional point of view, from a human rights point of view and from the point of view of criminal law. I look at the law from the point of view of an ordinary citizen. I am not a lawyer, so I do not have the skills to put a legal argument, but I am very sure that the reasons why people are looking for change in the law are the reasons that I have identified.

The other interest I have is in drama and history. As I mentioned before, I was a drama teacher for many years. One of the things that I have been doing since I retired is preparing something for publication. It involved looking closely at the Christian context of *The Tragedy of Hamlet*. I would like to read the speech of the priest who conducted the burial service for Ophelia. I assume that all of you know the play *Hamlet*. Ophelia is drowned and the priest is convinced that she committed suicide. In fact, the text indicates that it was an accidental death.

I would like to read a little bit from that. The reason for doing this is because I think that it gives you the hundreds of years of background to the law as it currently stands. It is a very old law. Laertes, Ophelia's brother, says:

> What other prayers will be said?

The priest says:

> The funeral has been as generous as we could make it. How she died is uncertain. The king's command has overridden church practice. She should have been buried in unsanctified ground until judgement day. Instead of charitable prayers, rocks, flints and pebbles should be thrown at her. But she has been allowed the prayers and ceremony of a virgin, a young woman's adornments and the public tolling of the bell and burial.

Laertes answers:

> Can't anything more be done?

The priest says:

> No more can be done: we would be insulting the service of the dead to sing a requiem and such rest to her as we would to people who died peacefully.

I will hand that out. I have copies for you.

THE CHAIR: Thank you.

Ms Arthur: That was 400 years ago. In fact, religions of all kinds have taken the same sort of view of anyone who ends their own life. One of the things that I have found, and that I have identified in the submission that we made, is that there is a huge contradiction between section 16 of the Crimes Act and section 17 of the Crimes Act. Essentially, we have section 16 in place, and section 17 takes us back to forcing people to die of disease and punishing those who want to end their own lives. That is the core of the problem that we are dealing with in changing the law.

I have a few other documents. This is a message from His Holiness Pope Francis to the participants in a European regional meeting of the World Medical Association. I included the document from the Vatican on euthanasia. While this document softens that position, the statement here still indicates that the church expects that people like you, the authorities, will do the right thing and maintain the law as it is. I would like to submit that.

THE CHAIR: Thank you.

Ms Arthur: The other thing that I want to submit is Dying With Dignity's proposal for an alternative way of dealing with death and elective death. We believe that section 16 continues on, and, between them, by not changing the use of the word "suicide", even though ending your own life is not a crime any longer, the law continues to promote the idea that ending your own life is an act of murder. So there is a high level of contradiction there. People are forced to hang, gas or shoot themselves if they want to end their lives. That is completely wrong and, to my mind, an irresponsibility on the part of those people who made the law.

Once section 16 was passed, it seems to me that it was the responsibility of parliaments everywhere to provide proper care for people who wanted to end their lives. We are including that as well, for your interest.

THE CHAIR: Thank you, Ms Arthur. Before we go any further, I have two very quick statements. I would like to pay my respects to the custodians of the land on which we meet today, the Ngunnawal people, and pay my respects to their elders, past, present and future, and to any Aboriginals and Torres Strait Islanders that may be with us today.

I would also like to make a brief statement in that I have known Ms Arthur for many years, but I do not believe there is any conflict. To get us started with questions today, I might throw to Ms Cheyne.

MS CHEYNE: Ms Arthur, how many members does Dying With Dignity ACT have?

Ms Arthur: It varies. When we were members of the Voluntary Euthanasia Society, we had about 170 members. In 2012 we became separate from them and incorporated in the ACT. Since that time our membership has varied. I think the current membership is 88, but when you include couples it usually goes over 100-plus.

MS CHEYNE: How many people do you normally get along to a meeting?

Ms Arthur: For ordinary meetings, we get 20 to 30. At general meetings we hope to get more—I would say 30 to 40.

MS CHEYNE: A good portion of your submission deals with an elective death unit. Are you able to expand on that a little bit and on where that idea has come from? In particular I note that it talks about a whole new arm of medical professionals who are trained in assisted dying. Why would that be appropriate, rather than have existing doctors carry out this work?

Ms Arthur: There are lots of reasons. Over the last eight years I have been involved in the World Federation of Right to Die Societies. We are a member of that group. I have travelled to conferences across the world and I have also read about the different approaches that different groups have taken. The country that I was most impressed by was Switzerland. What happens there is that doctors prescribe medication, but they have private companies who set themselves up and they have volunteers who go out to people who approach them for what I call an elective death. The volunteers assess them, give them support if they think they could continue to live, and they help them to die if it is very clear that there is no option.

It seemed to me that that was a very good strategy because one of the things that was also very clear to me was that doctors are highly ambivalent, especially Australian doctors, about having to kill their patients. You will get the odd person like Philip Nitschke or Rodney Syme who feel comfortable with it; and I am sure more of them would. But it seemed to me unnecessary to create a situation of role conflict. At the same time I thought that volunteers giving assistance to die was perhaps a bit lax. Perhaps we should have people who are properly trained, especially if you are going to say—which is what I hope would happen—that we should not be forcing people to hang, gas or shoot themselves. We know that 1.6 per cent of people end their lives every year; it just does not change. It goes up and down and it varies, but it does not change.

Despite all the things that have been put in place, all the money that governments have thrown at it and all the help that people give to it, there are some people who are going to want to end their lives. You should have people who are properly trained to assist those people, to talk them through the issue and also to give them assistance to die if they need it, in the end, after all the talking.

Really, death is more about giving counselling support. I think the actual mechanism is easy. You do not have to have a doctor to end a person’s life. I go off and have a blood test every six months because I have type 2 diabetes. I have talked to them. They are trained to do that job. They are not nurses or doctors; they are just trained to do that job. I think that if you had people who were specifically trained to do that job, you could work on offering compassion, offering support and offering the right kind of medication. You could offer an elective death unit, to my mind, which would allow people to have their families with them. They could talk through the issues; if they are not dying, they could talk through the issues which make them feel that they want to die.

MS CHEYNE: If this model was not feasible and it did fall to existing doctors, do you believe that conscientious objectors should be able to refuse to provide voluntary assisted dying services?

Ms Arthur: I do not think, in a democratic society, that you could do anything else. I think you would have to.

MS CHEYNE: If they did refuse, should they be required to refer that person back to perhaps a central body or to another doctor?

Ms Arthur: In the ACT that probably could be coordinated. You could probably have some central mechanism whereby people could say, “I need a doctor.” You could do it through the normal mechanisms of contacting someone involved in health through the ACT to do the mechanism of your inquiry support.

MRS DUNNE: I would like to go back to your discussion in relation to suicide. I am trying to delve into what seems to be a bit of a disconnect. On one hand governments across the world spend a lot of money on suicide prevention; on the other there is pressure from other groups to allow suicide, of a form, in particular circumstances. In public policy terms, how do you think that a government can negotiate that mire and say, “Here is a set of circumstances where we think that suicide is inappropriate, and we will spend a lot of money to prevent it; whereas here is a set of circumstances where we think it is okay and we will at least spend some money facilitating it”?

Ms Arthur: That is why I proposed the elective death model.

MRS DUNNE: What is the distinction between suicide and elective death, in your mind?

Ms Arthur: To my mind I do not believe that a person who wants to end their life is committing an act of self-murder. I believe that they are choosing death. That is why I called it an elective death.

MRS DUNNE: It is a very fine distinction. Someone who is physically healthy but mentally unwell and feels that life is not worth living could be said to be choosing an elective death.

Ms Arthur: Yes.

MRS DUNNE: Where is the distinction?

Ms Arthur: The distinction lies in the law itself. Section 16 says that it is not a crime to end your own life.

MRS DUNNE: But in public policy terms we spend a lot of money trying to prevent people from doing that. I am not talking about the legal aspect.

Ms Arthur: That is because—

MRS DUNNE: I am talking about the social aspect and the public policy aspect; we spend a lot of money.

Ms Arthur: Yes.

MRS DUNNE: Everyone is constantly looking at our suicide rates and saying, “They’re going up,” “They’re going down,” or “If they’re going up, what do we need to do to rectify that?”

Ms Arthur: I think we have to accept it. I think we have to accept that there are always going to be some people who want to die at some point in their lives. In having an elective death unit and making it publicly available to people, I would suggest that people would come to it and that, with good counselling, most of those people who were not dying of a physical disease or a very destructive mental illness would choose to live, because I think that we are programmed to live. Human beings are programmed to live for as long as it seems reasonable to do so. The law already says that it is not a crime, but the social issue is that it is treated as if it is a crime.

I think the setting up of suicide prevention mechanisms avoids dealing with the reality that people who actually really want to die will go ahead anyway. They will find a mechanism. Depending on how much they feel connected with their families—I am thinking about the sorts of incidents that I have heard about—often the suicide will be a violent one. Over 50 per cent of suicides are by hanging. Of the people that I have spoken to, it has been about people shooting themselves in the most horrible and gruesome ways.

If people get hold of those mechanisms, they feel that they have no-one to talk to; they feel that people are rejecting the whole idea of them wanting to die. It is like a taboo. No-one talked about sex in the past. Now, you can't go and talk to your doctor about the fact that you want to die because you put the doctor in a compromising position. If you talk to your relatives, they say, "No, you can't die." How can you talk to anyone about it if everyone is absolutely committed to you living? It is very difficult. We put people who really want to die in a terrible position by being in denial about it.

In terms of making the transition, that is the hard part. I acknowledge that our proposal is a hard one. It is normal for us to accept that taboo as something that we should all live with. I am saying that I think it is time to move away from that and to say that, with the taboo about not wanting to live, most of us want to live and we are programmed to live, but there are some people who, for some reason or other, are often confronted by something or they live with a slow sense of depression, of not wanting to be here or whatever. All of those things apply. I am not sure whether I have answered your question.

MRS DUNNE: Where would you envisage that this state-sanctioned facility would be set up?

Ms Arthur: We have three hospitals. It seems to me that this is really a health issue. At the end of your life, you are dying. I propose that you would go to your doctor. Your doctor will have done all the tests for you. They are going to be saying to you, "I think this is a situation where you've got to face your death." You can say to your doctor, "I would like a referral." In that situation you would just get a referral to the elective death unit.

In the case of someone who is not dying, they would go to the elective death unit and they would be taken through those steps that I have identified. I think that there would be very few people who would, after those steps, still be saying, "I want to die." I have seen that, even in Belgium and Switzerland, they are very careful about whether they allow it for whoever comes along.

I will give you an example of when I went to a conference in Zurich. One of the counsellors was a minister. I think he was a Methodist of some kind and he had two people that he was counselling. One was a man who was very highly disabled. He was living with his family. The other was a young woman who had two children and who had cancer. He counselled both. The young woman said, "I don't want my children to see me go through the ravages of cancer." So they took her on. Dignitas took her on as a candidate for death.

With the young man, they supported him out of his house where he was living with his parents. They found him a unit. They helped him to get in contact with a girlfriend. They helped and supported him with his daily life, and he was able to live. He might have put a rope around his neck if he was living in Australia. He might have picked up a gun if he was living in Australia. But because he was there in Switzerland, he could talk to someone who was not afraid of the idea that he wanted to die, and he was helped to extend his life.

That is how I see it working. We would have a proper facility and, as I think I said in the submission, these initial units could be established by the government firstly and they could be sold later. They could become private organisations.

MS LE COUTEUR: Dying With Dignity is clearly part of an Australia-wide organisation?

Ms Arthur: Yes.

MS LE COUTEUR: And given that we have the impediment with legislation in the ACT—I appreciate that you think it is unconstitutional but we have heard evidence from other people who think it probably is constitutional—have you any idea of the appetite around Australia for change in the law in the ACT?

Ms Arthur: This is the—

MS LE COUTEUR: The Andrews bill.

Ms Arthur: The Andrews bill, yes. I am still not giving up on that. I have received various advice, some of which has been completely irrelevant, and I am somewhat surprised by some of our lawyers. And others have given me advice about what to avoid if we were to go to the High Court to make a change like this. I think there are a couple of things I am still looking at.

The fact that we have got yourlastright.com as an organisation that we are allied to means we would talk to them about the possibility of their support for a legal case. The issue is of standing, if you wanted to make a legal case in the High Court. What I would say is that the alliance with yourlastright.com has been there since 2006. I think that we can say that we, as a group, have shown commitment to making change in the law so that if we were in a situation that we could go to the High Court that is where we would go.

We would try to make change around the country to the laws that are equivalent to section 17 of our Crimes Act. There are a couple of reasons. One is that it forces people to die of disease and it forces people into being punished if they choose to end their lives. Personally I see hanging, gassing and shooting yourself, being forced into those options, as being a form of capital punishment and I personally do not see dying of disease as a great thing to do. I think most people will be philosophical and probably go that way, but I do not see why anyone should die that way. I think it is a horrible thing to do to human beings.

I have actually looked at a good deal of the record of speeches on the Euthanasia Laws Act. A good number of the reasons why people did support that act were religious reasons. If we were able to draw on the discussion at the time then I think we could show that it was for religious reasons that it was passed, and there is a section in the constitution that does not allow religious observance. I think that what is going on is that the current law is based on a religious observance.

There are other things that I think we could do as well. I have got another thought about how we could argue it in the High Court. As I said, I have not given up yet.

MRS KIKKERT: Thank you for being here this morning. How much does an elected death cost?

Ms Arthur: I guess what you would have to do is make a comparison of the current costs associated with death and dying. It would be much greater than an elective death. Initially you would have the cost of setting up the boarding and employing staff as required. But you would not have people taking a long time to die. Nembutal could be purchased through the hospital, and that is currently done in other parts of the world. It is relatively cheap.

MRS KIKKERT: Do you know how much? Have you travelled around the world and have you inquired about how much it will cost an individual or families?

Ms Arthur: I do not think it is very expensive.

MRS KIKKERT: Can you put a dollar sign on it, please?

Ms Arthur: I cannot personally put a dollar sign on it, but you can check. It is usually used in Oregon and it is used in Switzerland. Both of those places could provide you with the figure amount but it is not expensive. The medicine itself is not expensive. If, for instance, you go to Switzerland it is highly expensive because you have got the flight. You have got your body to be transported back. You have got all the reports that have to be done et cetera.

Here, if you followed the suggestions that I propose, the doctor would give you your referral. You could choose to use that referral or not. You just go along, make your appointment. Most people die within an hour and your elected death unit would contact the funeral service and your body is off to wherever. In fact, it could be quite cheap.

MRS KIKKERT: I am assuming the doctors would have to charge a fee for their service for ending somebody’s life. It would not just be the medication.

Ms Arthur: No, the doctor would not be ending—

MRS KIKKERT: They would not charge a fee?

Ms Arthur: No. Your doctor—

MRS DUNNE: It would not be on the Medicare schedule?

Ms Arthur: Yes. You would have been going to your doctor for, say, the previous six months. You are dying of cancer. Let us say it is cancer of the pancreas. You may die within three months. You may have been going to your doctor regularly on that basis. You will have been given tests and so on. Your doctor will give you a referral. You would go to the elective death unit and there would be staff who would just be there to hand you the Nembutal and that would be it.

THE CHAIR: And you would take the drug yourself?

Ms Arthur: Yes.

THE CHAIR: As is currently proposed in Victoria. They are not saying an elective death unit but they are saying you must be well enough and fit enough to take the medication yourself.

Ms Arthur: Yes. It might be possible. One of the advantages of having an elective death unit attached to a hospital is that it might be possible that the person could not swallow. One of the doctors from the hospital might be involved in giving assistance. In Dignitas they have developed little machines that you can use and they always encourage self-death insofar as it is possible. The model that I am proposing would remove the doctor-determined or inflicted death. "Inflicted" is the wrong word.

MRS KIKKERT: I understand. In your submission you encourage support for elective death on Medicare. Could you elaborate on what you mean by that?

Ms Arthur: Just that it would be accepted as part of the support that Medicare would provide. It is not—

MRS KIKKERT: For the drug to end somebody's life?

Ms Arthur: For the drug and perhaps for the process. It would be relatively cheap, I think, to do. And in comparison with the sorts of things that people go through with their health towards the end of their lives now, it would be very cheap.

MRS KIKKERT: A lot of people would have an issue with that because they are contributing financially to somebody's death, which is against their faith, their belief. What do you have to say about that? You said in your opening statement that you are looking to the bigger picture after you retire, and that is death. What do you think about saving your own money for the drug and for the treatment and for the whole process?

Ms Arthur: I personally am indifferent. I think that there are some people who are on pensions who would find doing that difficult. That is why we have suggested that. But if it was unfeasible to have it on Medicare I do not think that it would be impossible. We all die. I guess the argument for a person of faith would be that they would be supporting the premature death of another individual—and would that involve them in some kind of murder? Is that the kind of argument you are suggesting? I guess that would be just something that would come down to a vote, a matter of a vote.

THE CHAIR: Thank you so much for appearing today and letting the committee ask their questions. When available, a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections, should they be required. On behalf of the committee, I would like to thank you again for coming in and chatting with us today.

MESSENT, MS PETREA, Regional Director and General Manager, Client Services, Dementia Australia

JONES, MS MAGGIE, Consumer representative, Dementia Australia

THE CHAIR: I welcome the witnesses from Dementia Australia. Before we start, can you confirm for the record that you understand the privilege implications of the statement in front of you?

Ms Messent: Yes, I have read it.

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

Ms Messent: Yes, I do. Dementia Australia formerly was Alzheimer's Australia. That is the peak non-profit organisation for people with dementia and their families and carers. We represent more than 425,000 Australians living with dementia and an estimated 1.2 million Australians involved in their care.

Dementia Australia works with individual families, all levels of government and key stakeholders to ensure that people of all ages with all types of dementia, their families and carers are appropriately supported at work and at home, including residential aged care or in their local community.

Our close engagement with consumers means that we are an important advocate for those impacted by dementia. We are also well placed to provide input on policy matters, identify service gaps and draw on our own expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

As I said, it is estimated that there are more than 425,000 Australians living with dementia in 2018. Approximately 25,000 of those are aged under 65, who have young onset dementia. Without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056. In the ACT there were an estimated 5,369 people living with dementia in 2017. That number is expected to increase to 7,353 by 2025 and to 16,313 by 2056—unless there is a medical breakthrough.

In respect of the rates of growth in the ACT, the numbers predicted to have dementia are higher than the national average. Therefore, dementia poses a unique challenge for Australians, with its increasing rates of prevalence and the personal impact on carers and their families, not to mention the economic costs and social implications. The number of older Australians with dementia is growing exponentially. The core business of both residential and home-based services increasingly includes providing care to people with dementia. When you consider that more than half of the people in permanent residential care have a diagnosis of dementia, it is understandable why the subject of this inquiry is an issue that has long been part of our advocacy.

Dementia is currently the leading cause of death in women and the second leading cause of death in Australians overall. It is the leading cause of death in people in permanent residential care. There is evidence to suggest that people with dementia may experience poor quality care at the end of their lives. Issues can include inadequate pain management, inappropriate hospitalisation, medical intervention and a lack of timely and appropriate consultation with a person with dementia or their family carers over their choices regarding end of life.

Furthermore, there is a lack of appropriate emotional and informational support provided to family and carers during the end of stage dementia. New data released by the AIHW shows the number of older people who live their final days in an acute care setting. Last year half of the people in permanent residential aged care who took hospital leave died in hospital. Similarly, for about one-third of those who last year had aged-care packages death occurred whilst on hospital leave. These statistics highlight the inadequacy of end of life care and services across our aged-care systems, be they residential, aged or community-based care.

As stated in our submission, a good death for people is unlikely to happen as a matter of course. A dignified death requires proper planning and support to ensure a person’s wishes are respected. It requires an advance care plan and nomination of a guardian in the ACT to enable a person with dementia to ensure their preferences are known, should a medical or end of life decision need to be made after they have lost the capacity to make that decision.

We should also ensure that people who receive the diagnosis of dementia in the ACT are supported to make informed decisions around the end of life care. Receiving a diagnosis can be a very challenging time for any family. We have to be sure that people have the support they need to navigate through not only the personal implications of that diagnosis but also the harder challenges of discussing end of life care for a terminal neurodegenerative condition.

In the ACT, Dementia Australia does provide some peer support workers for people living with dementia, but it is usually in the early stages of their dementia—not so much around the end of life and progressive times of their care. Our consumers have told us that they want palliative care that focuses on relieving the symptoms experienced by the person with dementia, rather than trying to cure the condition or delay the progression of terminal disease. The care should also provide emotional support, information and practical support for families and carers.

Consumer choice and informed decision-making should remain paramount in any decision about end of life care. Therefore, Dementia Australia supports and advocates for the right of people with dementia to exercise their choice at end of life, including in regard to future voluntary assisted dying legislation in the ACT.

In our submission we also highlight the complexities of proposed assisted dying legislation. As an organisation, Dementia Australia is neither for nor against voluntary assisted dying. We acknowledge the inherent challenges in the potential voluntary assisted dying legislation, particularly in its application to people living with dementia and other cognitive impairments.

For example, who would decide when it was time for a person with dementia to end their life if it was deemed that they had lost that capacity or the decision-making ability to do so? Timely advance care planning and high quality palliative care therefore remain the preferred methods of ensuring quality end of life for people living with dementia.

Individuals in the early stages of dementia should be supported and encouraged to participate in advance care planning to express their views about medical treatment and their preferences about end of life treatment. It is timely that this hearing is taking place during National Palliative Care Week.

Dementia Australia would like to take this opportunity to reiterate that people living with dementia and their families and carers need to be provided with sufficient information and support during the diagnosis of dementia in order to take those appropriate steps around advance care planning. Thank you for the opportunity to speak to this committee.

THE CHAIR: Thank you so much, Ms Messent. I want to ask a couple of questions that you may or may not be able to answer. In your submission you talk about there being a lot of people with Alzheimer's or dementia living in residential aged care. We have heard some witness testimony that the palliative care offered in residential aged care is not necessarily that great. Do you have any comment about that?

Ms Messent: Yes. I think that in talking about additional support for palliative care that we believe the whole industry is in need of, part of that obviously is in the residential aged-care sector. So I suppose we are very much in favour of supporting the ability for residential care and other care environments to build their capacity to deliver better palliative care. That is how I would answer that. Obviously, we would be very happy to be a part of that capacity building, as other organisations probably need to be as well.

THE CHAIR: I think I also noted in your submission that there is no specific palliative care aimed at people with dementia. Palliative care is a bit more related to terminal illness than to cognitive impairment.

Ms Messent: I guess historically it seems to have been focused on those other sorts of terminal conditions. With the increased awareness about people dying from dementia and it being one of the leading causes of death, I think we have to start thinking about some specific services around it. Obviously, there are some particular challenges around palliative care and what services and so forth you are providing for people who having difficulty making decisions, accepting treatment and accepting assistance full stop.

THE CHAIR: Finally, noting the time, you also said in your opening statement that some of the issues arising from supporting voluntary assisted dying for people with dementia can be that cognitive impairment.

Ms Messent: Yes.

THE CHAIR: But you also stated that Dementia Australia are more supportive of just choice in general, rather than looking at one side or the other. Is that correct?

Ms Messent: Yes, and I guess the challenge is trying to determine that choice for people with dementia, when they are capable of making that choice, as being the best opportunity to determine their preference for how they want to die or how they want to live out their life. Notwithstanding that, people can obviously change their mind as things go on. I think that is probably one of the biggest challenges in this sort of legislation.

MRS DUNNE: I continue from the questioning of the chair. Is Dementia Australia able to quantity the palliative care gap in residential aged care or in the aged-care system?

Ms Messent: Probably not quantify. It probably is not just around residential care either, but that is obviously where many people with dementia do end their life. Many of them also move out of there to go into a hospital environment as well, I guess because of the fact that they probably do not really have the capability to do that job well. There is a recognition amongst themselves that they would need support during that phase of a person's life.

MRS DUNNE: So recognition by the aged-care facility or by the family?

Ms Messent: Both, I would say. Sometimes it is by choice, or the family say that they would like their person moved and seen by somebody. Other times it would be the facility, I guess, advocating for that as well. I think that residential aged-care facilities, obviously like most people in the care industry, want to do the right thing for people. They try to do the best they can with the resources they have.

I guess the level of education and support provided in that environment is probably the main area where we see a gap. That is probably something that is a bit more quantifiable—the level of expertise, skill and knowledge around palliative care and particularly around pain management and assessment. That is one of the big areas that we see—

MRS DUNNE: Are you saying that that is not necessarily universally seen in aged-care facilities?

Ms Messent: Yes, that is correct.

MS CHEYNE: I have a similar line of questioning. Due to the nature of dementia, you mentioned that people suffering are more likely to receive that unwanted life-prolonging treatment and to be essentially denied a choice as to how and when they die. Can we address this by promoting the use of advance care planning?

Ms Messent: Yes.

MS CHEYNE: If so, how can we do this better? Last week we heard from Doctors for Assisted Dying Choice, who said that perhaps we should be providing incentives for doctors to have in-depth conversations with people, and promoting the use of that. Is that something you would support, or do you have some other ideas?

Ms Messent: We would support early advance care planning in any circumstances, and for anyone with a terminal disease. We would consider it to be extremely important for people with dementia because very often they lose their decision-making capacity and cannot do it at a later stage or find it much more difficult to do as the disease progresses. With doing it early, whether that is through a combination of the points when they might see health professionals or services like us, the earlier the better.

Sometimes, obviously, the timing of that, as we have said, is difficult because there are so many other things going on for people when they receive a diagnosis of dementia. That may or may not be something they want to talk about first up. It certainly needs to be sometime during that early phase of diagnosis so that it gives people the best opportunity to sort through and process the information, as well as having better options in the first place for whilst they are living. We would probably emphasise that with the use of resources, if we could improve the way that palliative care is available for people with dementia in the first place, there may not be so much discussion around this. There would still be a discussion.

MS CHEYNE: What does a good death look like for a person with dementia?

Ms Messent: That would be a very good question to ask of our consumer rep.

Ms Jones: My husband, Gordon, had Lewy body dementia, which is kind of a combination of Alzheimer’s and Parkinson’s. It is like a double whammy. It involves both physical and cognitive decline, and the deterioration tends to be more rapid than with Alzheimer’s. Gordon died just over two years after he was diagnosed.

He spent the last six months of his life in a wheelchair and he also had to have a catheter, which made him very vulnerable to urinary tract infections. He was in a residential care home for four months but came home for the last two months of his life. He was frequently hospitalised with pneumonia and he also found it increasingly difficult to swallow. I understand both of these side effects are relatively common for all forms of dementia.

For the last month of his life he needed to be on a liquid diet. About five days before he died, he found it impossible to swallow even water. That is when home-based palliative care began for us. He was placed on a drip to keep him hydrated and given medication to ensure that he was pain free and as comfortable as possible. He became much calmer than he had been for some time before, but it was a kind of serene calm, not the kind of robotic state that he was in when they briefly put him on an anti-psychotic drug when he was in the care home.

He was able to die in the comfort and familiarity of his own home. Given the dreadful ordeals that he had had to endure during his illness, it was as dignified and as peaceful a death as we could have hoped for. He did have an advance care directive, which we did in the early stages of his illness. I also had enduring power of attorney. We had also been able to have a number of conversations in the years before, when we were both well, so I was well aware of what his wishes were and that they mirrored my own. We were both firmly of the belief that it is quality, not quantity, of life that matters most.

THE CHAIR: Thank you for sharing.

MS LE COUTEUR: There is a lot to talk about in the discussion. One of the saddest things is the small number of dementia sufferers who actually get palliative care. One area which you have not talked about at great length is that, clearly, under most legislation for voluntary assisted dying, once you have dementia you are out of the possible cohort.

This is a question I have asked of a lot of people. I can see reasons for and against. Clearly, you have put forward some reasonable points as to why that is unfair. Have you had any thought about for how long in advance people should be able to say, “It’s within two years of my expected death,” or “I’m in a particularly horrible situation,” so that, despite the fact that their mental capacity is not what it used to be, they could still take advantage of a voluntary dying scheme?

Ms Messent: As with many things, it would need to be on an individual basis. The length of time before death is hard to predict with something like dementia; even in this situation it was quite difficult to predict. That is probably not as much of an issue as making sure there is a gauge about the quality of life, and it is about where it is at, rather than the length of time that people have.

We have also, through that submission, shown how our own consumers differ in their opinions about how they want this to happen. You can’t just say that once people reach a certain point then they should or should not be able to make a decision. Some people think they need to be able to make that decision, or they want that decision to be there. Others do not think it should be a part of it. We would probably say that, if legislation is to be reviewed, people with dementia should be included in that review so that they and their carers can have that discussion themselves.

MS LE COUTEUR: You are saying that people should be consulted in terms of the legislation, but the legislation will still say something; based on other legislation, it will be that once you are cognitively impaired, voluntary assisted dying is not an option for you. Would you think that was reasonable?

Ms Messent: In itself, obviously it is. If you can’t make an informed decision about something like that then you would be excluded from it. That makes complete sense. For our consumers, there is an opportunity to utilise the advance care directive somehow in that process. I would not necessarily want to say how that should be done. A lot of things would need to be considered in how you would do that and how you would protect the wishes of people. It is a bit like what I said before about how people can change their minds. There would need to be a review process of advance care directives so that people have the opportunity to consider things as they go along, and as far along as they possibly can. There are people with dementia that may be in the phase of dying that could still make decisions. Excluding them categorically from this process is probably not something that we would support, either.

MS LE COUTEUR: Also, quite a number of people with dementia actually die from something else.

Ms Messent: Yes. That is a good example.

MRS KIKKERT: You state on page 7 that there are potential risks to the community and an individual if euthanasia is introduced, and you cite the possibility of coercion. Could you explain to the committee how coercion might occur in the case of a person with dementia?

Ms Messent: It is not necessarily obvious sometimes. Even for people with dementia and their carers there is quite a bit of stigma still around the disease. I think it is one of the most feared diseases for older people in the community. Obviously, partly because the quality of life that people can sometimes live is diminished, I suppose we would like to change some of those stigmas. You can live well with dementia. You can live quite a long part of your life in a very good state with the right supports at the right time.

It is more about, I guess, changing the focus because of the whole issue of undervaluing older people and people with cognitive impairment and disability in general. They are the things that we are referring to. Families and people themselves form views about whether they should or should not be here. And it is that subtle social coercion mainly that we would be referring to as well as occasional other signs which are probably a bit more obvious.

THE CHAIR: I have a very brief question. Ms Cheyne earlier was asking about a good death. And thank you again so much for sharing your story; it really is helpful for the committee. One of the things you said in your submission was that it is a myth that people with dementia cannot feel pain. We have had a palliative care specialist come in here and say—I am probably not going to get these words exactly right, so I apologise to him—there is no case where palliative care does not work. They will always make sure that—

MS CHEYNE: He said it was a matter of managing the symptoms and that sometimes they just do not get the understanding of the symptoms right. But if they do then palliative care can solve all pain and suffering.

THE CHAIR: There are some cases of dementia sufferers that are at the end of life and are not able to speak and are not able to express their concerns, including their pain. Would you agree with that or do you think that there are times when people, particularly with dementia, still feel pain at that very end stage of life? Ms Jones, that might be something that you could also add to.

Ms Messent: I guess it depends on where, from whom and how they are receiving that type of palliative care. Obviously, if you can assess and identify the pain that is existing in the first place, which is quite challenging because of people's cognitive and communication issues at the advanced stages of dementia in particular and sometimes even in the earlier phases—knowing that there is pain—the recognition of pain is the most important thing, and always be looking for it, because it is probably very, very prevalent in people with dementia throughout their journey with dementia.

Yes, the difficulty is that we do not have those palliative services as involved as we would like, that there are not as many of them around as there could be and that people with dementia and their carers do not necessarily seek the services because they do not see dementia necessarily as a palliative care issue themselves. They just see it as part of old age and, like I was saying before, we just leave it.

THE CHAIR: Do you have anything to add?

Ms Jones: It is very difficult to tell whether they are in pain or not. I knew Gordon better than anyone—

THE CHAIR: Absolutely.

Ms Jones: But I could not tell. He was shouting; he was quite distressed a lot of the time and I worried a lot that that was because he was in pain. But he was given pain medication. It did not seem to make any difference. That was when the care home, when he became very agitated, put him on an anti-psychotic drug. And I am very much opposed to that.

They told me at the time that they were giving him a sedative and I said yes because he just was so upset and that seemed reasonable. But I would not allow it again after that, once I realised what it was. That is a very bad outcome, I think, for people with dementia. And it is often the thing that care homes, I suspect, give them because it makes them easier to manage rather than because it really benefits the patient. When he was given the medication by the palliative care team, his demeanour was, as I said, very serene and he was clearly not in any pain at that point.

Ms Messent: I was going to say, as opposed to something like an anti-psychotic, we would be advocating generally for pain medication. It is not going to do any harm at that point in time for people anyway. I guess that is how we always go.

MRS KIKKERT: Was he given anti-psychotic tablets and medications to reduce his anxiety or his pain or—

Ms Jones: No, his anxiety. He was very disturbed.

MS LE COUTEUR: I suppose the other point of questioning is: how do we improve care for people with dementia but before the last very short period, where we are talking about palliative care? As you were saying, your husband was in a care home for four months and it was not a very positive experience, from what you were saying. I can certainly talk at length about some negative experiences. Have you suggestions on how we better deal with people with dementia before the last couple of days?

Ms Jones: I do not know whether I will be very articulate, but certainly I think there needs to be a lot of improvement. The care home Gordon was in was not terrible. You hear awful horror stories, and it was not like that. They do not cater for the individual enough. And unless you fit into a certain sort of stereotype and you are compliant and not causing too much trouble then they cannot really deal with that very well.

They had lots of activities at the care home. That is one of the reasons I selected it. But Gordon was not interested in participating in any of those. And he needed, I felt, much more understanding of his condition and much more individual care to try to get to the bottom of what was causing his anxiety. He was certainly much better once he came home.

THE CHAIR: Thank you so much for speaking with us today. We really appreciate the insights that you have been able to share with us. A proof of transcript will be forwarded to you to provide an opportunity to check and, if needed, suggest any corrections. On behalf of the committee, I would like to thank you both, again, for speaking with us today.

Ms Messent: Thank you very much for the opportunity.

Hearing suspended from 10.48 to 11.01 am.

DODD, MS JUDITH
PAVKOVIC, MS KATARINA

THE CHAIR: I welcome you both here today. I know that you have both written individual submissions. We will be asking you each individual questions. It is just lovely that we can have you both at the table together.

Before we get started, could you confirm for the record that you understand the privilege implications of the statement that is set out there in front of you.

Ms Dodd: Yes.

Ms Pavkovic: Yes.

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

Ms Dodd: I could make a brief statement.

THE CHAIR: Yes.

Ms Dodd: I am here as an individual, also an ex-nurse of many years. I was a nurse for 40 years. I would just say two things. Firstly, I do not think we do death well in Australia, and we certainly do not do death well in the ACT. From my extended nursing and personal experience, I have lots of examples that I could give you for that. I feel we need to have a very long, complicated, difficult discussion about death, as a nation and as a territory. Secondly, my mantra would probably be "Choice is peace of mind." If you have choice, whether you choose to take up voluntary assisted dying or whether you do not, the fact that you have that choice is what gives you peace of mind. That would be my guiding principle.

Ms Pavkovic: I am here representing my dad, who had Parkinson's disease. He passed away a couple of years ago. The main thing that I want to get out today, and thank you for giving me the opportunity to come here and talk to you guys, is to make it known that I want to thank my dad as well, because he helped me get to where I am. He gave me the strength and the confidence to try and get the story out there and do what I need to do. He also gave me a story and a reason to help try and make a difference. I really would like to thank you guys for letting me be here.

THE CHAIR: Thank you both. Thank you for sharing, Katarina. I am just going to dive straight into it. Ms Dodd, in your very brief opening statement you mentioned choice. The committee was lucky enough to head down to Victoria and talk to some of the legislators involved with implementing the new legislation. Part of what they were saying was that overseas often people might go and get the drugs and be able to use them, but once they have them, they may never use them.

Ms Dodd: Sure. Exactly.

THE CHAIR: You said that in your submission, I think, as well.

Ms Dodd: Yes, I did. I think it is very important. When that time comes that you are not far away from death, you do not know what you are going to want to do, but it is good to have some choices so that at least you know that you will have that option to do A, B or C at the end. If you know you have no choice, it is not only a physical problem but an emotional restraint on your ability to have a good death. You need to be able to have a clearness of mind and a knowledge that if something goes not according to plan, you have options that you can choose. That is very important.

As a nurse, I have seen many occasions where people do not have a clear idea of what death will be because we are so divorced from death in this society. We are afraid of it. It is locked away. It is not something we discuss. We cannot even say “death” or “died”; we use euphemisms. I have seen families afraid of using the word, let alone coming to grips with the fact that they have a loved one that is going to die.

Until you actually get to that point, you have seen very little of what death can involve. Until you get there yourself and realise that maybe you should have made other plans, put other plans in place—if you do not have a choice, it can go terribly wrong and be a very unpleasant way to die for some people.

THE CHAIR: Utterly. Ms Pavkovic, I note that in your brief opening statement and also in your submission you talk a lot about your father giving you strength. You provided us with a video and you provided us with a whole series of questions, and I, for one, thank you. Does it give you the opportunity to think about what you might want? Your dad really did speak to you. Did you find it interesting that he wanted to talk to you about those sorts of things? We have heard a lot, as Ms Dodd has also said, that people are scared to talk about death.

Ms Pavkovic: I think it depends on the particular situation. Both of my parents were very protective of me. I am only 23 now, and he passed away two years ago, so I would have been 21, and he had been sick for about 12 years, since I was about 12. Having the conversation with your child at 12 is daunting. It is daunting even between family members who are the same age as you, let alone your child. The reality of the situation was that they did not really talk too much about it to me until I was older, until I was 18. They both do not have English-speaking backgrounds, so I was the one that was actually there at a lot of the appointments, describing a lot of the different things and the different plans and what could happen.

Drawing it back to your question there, I only found something out last night when I was speaking to my mum. She did not know that I did this submission. I told her about it and she read it, and she was so happy and so proud that I was here doing this today, so much so that she told me a little thing that I had never known: my dad asked pretty much weekly for my mum to kill him. That is quite a difficult thing. First, it is difficult to be asked—coming from my mother’s perspective—weekly, “Please kill me. I don’t care how you kill me. Please just do it. I’m begging you.” It took incredible strength for my mum to say no. She had been with my dad since she was 17. They got married at 17 years old. They were roughly 60 at the time when he passed away. That is a significant amount of time to be with a significant other, and he was pleading and begging, “Just please finish me because I can’t handle it.”

It is not as though he was easily able to communicate that. That was a belief that he had had since he was young, so that is why my mum would know that he was okay with making the choice. But with him, in particular, to spell out the words—in the end, he could not talk, he could not walk, he could not move, he could not clean himself. He did not have the dexterity to even write on an iPad. It was literally using one finger and pointing to a word on a chart. He literally had no choice. He had no ability to even make a choice. So, as you have read in the submission, the choice was made that he did not want to eat anymore because that was the thing that he could actually choose to do.

THE CHAIR: Choose.

Ms Pavkovic: This is not the first time I have tried to get my story out there. I had a particular experience on social media where I had a person comment on it, saying, "Well, if he really wanted to die, he should have just killed himself. There are many different types of ways to kill yourself." There are internet trolls. When I laid it out for him, I was like: "Look, if he had a gun he did not have the dexterity to pull the trigger. If he wanted to hang himself, and we have had people in our family do that, he did not have the dexterity to tie the noose. If he wanted to have the pills that he wanted, and he had them next to him every single day, like the pain medication, he could have, but he could not swallow them and he could not get them out of the container to put them in his mouth. He literally had no way to be able to even do that. This was the only way that he could have." Sorry for the long-winded explanation, but that is my experience.

MS CHEYNE: I have questions for both Ms Dodd and Ms Pavkovic. Ms Dodd, we heard from a palliative care service provider last week that there is no situation that palliative care cannot handle, that it is all about managing the symptoms. However, that was refuted by other witnesses, including Doctors for Assisted Dying Choice and the Nursing and Midwifery Federation. Given your almost 40 years of experience, are you able to tell us your view on that statement?

Ms Dodd: Yes. Where do you start? I believe that palliative care have the best intentions in the world and they all do a tremendous job. I saw it in action with my parents-in-law, and they were wonderful. But they are really only dealing with the physical suffering. From my perspective, I have seen situations where, even with the physical, on some occasions it is not sufficient palliative care.

But let us just say it is. The fact is that it is not just a physical thing; it is a mental and intellectual thing. Say somebody has wanted all their life not to go through those last few weeks with palliative care in place. Sure, they might be comfortable, but if they are stressed and anguished and they just do not want to be there, like this poor girl's father, then, comfortable or not, if you do not want to be there and you have not got a choice it is—distressing is hardly the word for it. This young lady has already described that very well.

It is more than just a physical thing. That is what I think the palliative care people do not get. They do not get that if someone is lying there, they are looking happy and relaxed and they are sedated, and everyone in the room has ticked the box—comfortable, tick; no pain, tick—that is fine, great, but that is not all there is to it. There is so much more to it, let alone the situations where the pall care does not really cut the pain. It does not, occasionally.

So there are two aspects to that, but I think really there is the mental anguish, the distress and the patient's dignity. It is a matter of dignity. I am not describing it very well, but if you had a long-held belief for all your years of life that you did not want to be lying in that bed in that position, comfortable or not, and that was what happened and you were made to go through that, how is that a good death? It is not a good death. I have had so many people say to me or to their relatives, just like with this young lady, "Please, let me go. Let me go." I have heard it so many times as a nurse and as a daughter of two parents. I have heard it so many times. You can be comfortable, but there is more than just physical comfort in a death, and that is what we are missing.

MS CHEYNE: What is the impact on you and other health professionals when you are asked, "Please put me out of my misery," or "I just want to die"?

Ms Dodd: It is very distressing, but you cannot show your distress. You have to show empathy. Sure, you can show empathy, but you feel so inadequate. You feel completely inadequate—especially someone like me, who has always been a great believer in euthanasia, for want of a better word—to see somebody go through that and not be able to help them. In days gone by we might have given them a little bit extra morphine to maybe speed things up. You cannot do that anymore. I am talking decades ago. Doctors would prescribe a little bit more morphine if that was the case, but you cannot even do that these days. The palliative care people have that all under control now. It is a very distressing thing. It is difficult to know what to say to patients when they ask you that sort of thing. It is even more difficult to handle the family, when they can see the distress, but you just have to do it.

MS CHEYNE: What are the long-term impacts on health professionals when they are, going home each day—

Ms Dodd: They burn out. I have not worked in oncology for any length of time; I used to work in coronary care back in the 80s and 90s, for about 15 years. We had a lot of coronary patients that died, patients we knew well who came back in regularly. We saw them slowly deteriorate. You would get very attached to them and their families, and they came in for the last time and you would have to help them through that. They were not demented; they were with it completely most of the time, that sort of a patient anyway. So they knew what was going on.

You get attached to these people and you get attached to their families, which is good in a way because they feel they can trust you and they know you are doing whatever you can for them. But there is a limit to what you can do, and to die of literally being unable to get enough oxygen—which is what happens a lot of the time when your heart is failing, your heart and lungs are starting to fail and you cannot get enough air—it is like drowning really. Pal care is great; it makes them feel better, but not if they do not want to have to go through that day and night, day and night, day and night for maybe weeks until the end comes.

So staff burn out; they move on; they go to other areas. There is only so much you can wring out of yourself after years and years of looking after that sort of patient and those sorts of families. They move on to other things or, in fact, they leave nursing. You see so many people burn out. The hours are rubbish. The pay is rubbish. They move on to public service, they get projects or whatever, and you lose really good staff. It is very sad, but that is nursing. That is a lot of jobs.

MS CHEYNE: Ms Pavkovic, I have questions relating to your specific experience. If at any moment it is distressing, please let me know. Throughout your story it is clear that there were some particularly distressing times during your father's illness and the process of his dying, including that you do not think your father necessarily got relief from palliative care and was struggling to breathe at points and, as you mentioned before, even to physically move or to exercise choice or make his feelings known about what was happening to him. To you, what would a good death for your father and also for your family have looked like?

Ms Pavkovic: I am not actually sure if I wrote it in my submission, but I work in a small business, so there are not too many staff members who can cover if you have a situation that happens. I work in a taekwondo company and we are representing Australia quite often. We have two teams and we have one team go overseas at one point in time and the other team looks after the club. While my dad was actually passing away, more than half of our team was overseas and so it was up to only about two or three people to look after this small business of running a few hundred people doing taekwondo classes.

Because of that situation I really could not not work. I had to work every single day leading up to his death. I worked the day he died. I worked the day after he died and I worked several days after he died. Because I had spent a lot of time with him in the palliative care unit, I could not justify leaving for so much time, especially when he had been in the process of dying for six weeks up until that point.

My manager's father passed away quite recently; it was something to do with his lungs. He had, I would suppose, a relatively quick death and a relatively perfect death. I am quite jealous of how he got to pass away because he passed away with all of his family members in the room with him, and everyone was smiling and laughing in the end. Even though he was passing away, everyone was together. My dad, he was alone for a lot of the time. Sometimes he was not. It was just me and my mum pretty much. In the end it sort of felt like he was alone, and he was struggling without the ability for me or my mum to be there for him in the end, which I feel like he would have wanted.

MS CHEYNE: It was a matter of when? You did not know when?

Ms Pavkovic: Yes, absolutely. We did not know when because, by virtue of him trying to starve himself out, he could have gone at any point in time. Coming back to your question, it would have been ideal if we had all been together, if we had all known when. But death is like that—you do not know when things are going to happen, especially when you do not have a choice. Literally you do not have a choice of what you are eating. You do not have a choice of how you can communicate. You do not have a choice in whether you can move from here to here with your hand. Coming back to the question, being all together would have been the ideal death.

MS CHEYNE: And having a time and a place?

Ms Pavkovic: Exactly. If I had known then I would have been able to organise work properly. I would have been able to care for him properly, given him the love and the affection that he needed, rather than him being so distressed. I suppose the horrible thing about it was that for about three or four weeks he was under this palliative sedation. I was looking at the hearings before, so I have a general understanding of what was said. He was under this palliative sedation for a lot of time and, you know, "That's not my dad". He was just, I do not know—

MS CHEYNE: A shell?

Ms Pavkovic: Not even—he was just locked in a shell. He wanted to come out, obviously. If we had known, we would have had better communication in the end. We would have been able to say goodbye properly. He would have been able to say goodbye properly, rather than what it was, I suppose.

MS CHEYNE: Ms Pavkovic, given the way your father died, both the suffering and the fact that you were not able to be there with him when he passed, what have been the longer term impacts on you and your mum?

Ms Pavkovic: I can liken it to PTSD. You have particular things that you remember and you almost associate them with other things that you can see. For example, my fiance's grandmother recently passed away. She also had a pretty good death; she died next to her daughter. But it is like PTSD almost. If you go into an old person's home, it reminds you of the palliative care unit. I see an older person or an older gentleman and it reminds me of dad and it makes me so upset. Or you see somebody who is struggling to move or has MS or a milder form of Parkinson's disease and you feel like this distressed feeling is overwhelming you a little bit. It brings back a lot of the older memories of the suffering you all had.

In particular, especially towards the end, it is important to note that it was not just him who was suffering. Of course he was suffering incredibly, but we all were. It is distressing to see somebody who you love and who has supported you most of your life just turn into something that he did not want to be. He had built a house. He was physically active. He did not want to just be locked away, unable to do anything he really wanted to do. That is quite distressing.

But the important thing to note as well is that there is always a positive in every negative. If he was not as he was, I would not have met my fiance. I would not have done taekwondo. I would not have represented Australia. I would not have had the confidence to be able to sit in front of all of you guys today. So a lot of positive things came out, even though there were quite a few negative things. But I choose to look at the positives, as much as I possibly can anyway.

MS LE COUTEUR: You talked about palliative care for the very last of his life, but from what you were saying—and this was also what Ms Dodd was talking about—well before the point of palliative care there were considerable issues. In your father's instance, he clearly, from what you know now, was expressing the desire to die. Ms Dodd, you were saying that many of your patients in hospital have said that. Do you think that in looking at end of life choices we need to change the palliative care system or extend the palliative care system? There seem to be more issues than just in the last very short period of time.

Ms Pavkovic: Do you want to start off? You have more experience, obviously.

Ms Dodd: I would just give a very general answer on that. As I said in my opening statement, we need, as a community, to have a really long, thorough discussion about end of life. Even “end of life” is a misleading term. We need to have a discussion about how we want our community to treat people that are in that early stage as well as the later stages.

We need to have things in place. We need to have options for people. We need to all come together and tackle what is almost the taboo that is death. It is a taboo, and it is not healthy. We need to all be made aware of the fact that death is not just something that happens on a particular day. It takes weeks, months and sometimes years for some people. We need to address how we are going to tackle any particular scenarios that might crop up and give people some sort of overall plan.

The advance care plan that we have in place is wonderful. It has been a great thing for the ACT to have the advance care plan electronically available to all patients that come into hospital. It has been a really outstanding thing to have achieved. I would like to see something like a voluntary assisted dying plan, if people want it, and what their short-term and long-term goals might be. I do not know what the answers are, but as a community we need to come together and form some kind of long-term plan for people and decide how we want to tackle that as a community. I do not have the answers, but I think we need to have that conversation and put a plan in place.

MRS DUNNE: Ms Dodd, you said you thought that—I am sorry if I am misquoting you—the term “end of life” was a misnomer. Would you like to elaborate on that?

Ms Dodd: As Ms Le Couteur was saying, end of life is not just the day you die. It is not just that. It can last for years. It lasted for 12 years in this young lady’s father’s situation. It goes on for a very long time in some people’s cases. That is a very distressing procedure, and I think we need to tackle not just the actual end of life but the procedure and the lead-up that go along with that and lead to that end of life. It is more than just the end of life. We need ways of tackling that short, medium or long-term range of options that people might be facing with their death or end of life.

Ms Pavkovic: From my experience in particular, as I said, our family came from a non-English-speaking background. They migrated from Serbia 30 or so years ago. I have always lived in Australia but they have not. We have had many points of contact with various health providers. We have had OTs, physios, doctors, specialists, palliative care nurses, physicians—all of that sort of thing.

If those people had been a little bit better equipped to bring up the discussion of something like this, we may have been better equipped ourselves. Both of my parents were very much in denial for most of the 12 years, even leading up to when dad was in hospital for the final stretch of time. Mum was saying, “No, he’s going to last for a long time,” even though he was already in the palliative care unit.

I remember when I was in high school I had a couple of teachers trying to help support me, and they were saying, “Maybe it’s not Parkinson’s disease. Maybe it’s Guillain-Barre, and he will be better in maybe a couple of months or a couple of years time,” or “Maybe it’s just MS and it’s not going to be so bad.”

We could have been better prepared if we had had those conversations a little bit earlier. As well, there was the fact that my parents were from a non-English-speaking background and perhaps they did not understand. I heard a lady in a previous hearing say something about the penny dropping. The penny had not dropped that Parkinson’s was almost like a death sentence. It took him 12 years to get there, but if we had had more conversations earlier on, it would have been better.

Palliative care, as it currently stands, is pretty good, considering the scope that it has to operate within. The nurses are lovely; the doctors are lovely. They help you out as much as they possibly can, within their scope. Maybe we need to extend the scope a little bit to be able to facilitate more things.

For example, one of the head doctors at Clare Holland House said something like if he had a little bit more money then he would be able to provide some help with the psychological background—as if to say, “Do you really want to die? Do you really want to do these things? Maybe I can help you.” And he did help the guy. That said, you should be able to try and do that with various people, but there are some people who are too far gone, like my dad was. He could not go paragliding even if he wanted to. He could not get out of his own bed. He could not go to the toilet by himself. He could not talk. He could not do anything. He could hear you. He could listen.

MS CHEYNE: How do you manage the psychological symptoms of that? You don’t.

Ms Pavkovic: You can’t. Just imagine yourselves not being able to move, talk, walk, eat—do anything that you enjoy doing. You are staying within your own body. You understand exactly what everyone is saying. You can formulate exactly what you want to say, but your body will not let you. You can’t manage something like that. You can try. You can try, absolutely, but you just can’t.

Going back to answering your question, I do not know whether extending or making palliative care more present for a person earlier on may necessarily help. I think making more people, as she was saying, more comfortable with addressing death, addressing how to deal with death and addressing the family and helping them to deal with death would be a better approach, in my opinion, because death is absolute for everyone. It does not really matter whether you are sick and you manage a plan to pass away. You can die from a car crash tomorrow. How is your family going to react to that? I think that making people more comfortable with the idea of death is a better approach. I definitely agree with what she was saying.

MRS KIKKERT: Thank you, Kat, for sharing your story; and thank you, Ms Dodd. Kat, you mentioned before that you like to look at positive things in life. What life lessons have you learnt from caring for your dad for many years? In particular, what sort of personality characteristics have you developed throughout more than a decade of caring for your dad?

Ms Pavkovic: That is a funny question because I was very spoiled. Pre 12 years old I was very spoiled. I got anything that I wanted. I was, I would suggest, like a definition of a rotten child. I would get anything that I wanted. I would cry if I did not get it, until I got it. I suppose I have a similar characteristic now, although it is a little bit more mature. I do not cry and I do not wait until I get it; I just work harder for it.

Going through that experience has given me a sense of independence that I definitely would not have had without him. For example, if my dad had not been sick, I probably would have done tennis instead. Who knows what would have happened there? Because he was sick, I ended up doing a little bit of taekwondo, and I ended up instructing at my classes, and now I am one of the team leaders there. I can now instruct and talk to in excess of hundreds of people, giving them instructions on how to get better and giving them confidence. I would not have had the ability to do that if he had not been sick. That is not necessarily a direct thing that I have had from him, but it is a related outcome because of that.

If I had not had this particular experience, I would not know what questions I need to ask of particular health professionals. Health professionals sometimes are more focused on health and they are not necessarily focused on the people or the understanding of it. They would say, “We’re just doing this,” and I needed to inquire, “Why? Are there any other better ways to do these things?” Now I have that skill that I can apply to further areas of my life in future, if needed.

I also would not have had the confidence that I would be able to do this. Because of all these things, I have dealt with various health professionals. I have dealt with the sometimes frustrating NDIS system as well. I have gained the ability of doing everything that I possibly can within my power to ensure that we have the best possible outcomes that we can have.

There are a few other things. Obviously, there are the more practical things. I know how to plan a funeral now. That is something that everyone will need and a lot of people will be very scared to face. I have that experience now. I helped my future mother-in-law; her mother passed away two or three weeks ago. I helped her to plan the funeral. I am not afraid of that sort of thing now, which is one thing that has come out of it. I am not afraid to try new things and try to do the best that I can with the situation. It is something that will happen for the rest of my life, and the rest of everyone else’s life, so I think it is just best to be comfortable with being uncomfortable.

MRS KIKKERT: Having great adversity in your life has actually turned out to be a blessing in disguise?

Ms Pavkovic: Absolutely. I would not even call it in disguise. There is a blessing in absolutely everything; you just have to look hard enough to find it. I have gained so much. I would have loved for my dad to have been here, but I am an amazing person because he had to go through that very terrible suffering.

MRS KIKKERT: He would be so proud of you.

Ms Pavkovic: Yes.

MS CHEYNE: I have a quick clarifying question on that line of questioning, Ms Pavkovic. With all of the life lessons, the experiences and the blessings from it, it seems to me that the majority of the things that you mentioned you still would have gained, even if a voluntary assisted dying scheme had existed; is that correct?

Ms Pavkovic: Absolutely. If we had had that scheme in place, I would have fewer negative emotions. You can see that I have not quite worked through all of them yet. I am okay with admitting that. I would have, I suppose, a little bit less anxiety over dealing with something like that. I am absolutely terrified that, if I eventually have children, I will have to look after them if they get sick. I am terrified of that, and that is something that I have to work through. Having said that, that might be a reality, and that is okay. Given that he had been sick for so long, I would definitely have gained all of these things. It just would have left me with more positive memories in the end.

MS CHEYNE: It was the ending, wasn't it?

Ms Pavkovic: It was just the ending.

MS CHEYNE: That is where the trauma lies.

Ms Pavkovic: Yes, absolutely. As I grow older, I have more and more limited memories of my dad. I have a little list of memories of him, in case I forget them over time. I have one amazing memory from when he was sick in hospital. That was when he spilled the secret that my fiance was going to propose to me at that moment. My fiance got angry and said, "He shouldn't have told you." But he did, and that was an amazing memory that I got out of it. But I could have had that memory if we had had this scheme in place and he had just had a chat to him. I do not think I gained a lot from going through such a hard, difficult process. I could have gone without it.

THE CHAIR: Thank you both very much for being here today and for sharing both your insights and your stories with us. The committee have enjoyed that. I note that there were possibly a couple more questions. I know I had a few more for you, Ms Dodd. Could we possibly write to you with some of those questions?

Ms Dodd: Sure.

THE CHAIR: Thank you so much. When available, a copy of the proof transcript will be forwarded to you both individually, to provide an opportunity to check the transcript and suggest any corrections, should they be required. On behalf of the committee, I would like to thank you both again for your stories and your insights.

Ms Pavkovic: I appreciate that it is very distressing to listen to so many different stories, opinions and views. Thank you so much for battling through and helping with what we need to get done.

MRS KIKKERT: We appreciate your time. Thank you for coming.

DWYER, DR TERENCE, Principal, Dwyer Lawyers

THE CHAIR: I would like to welcome our last witness for today's hearing, Dr Dwyer. Before we get started, could you please confirm for the record that you understand the privilege implications of the statement next to you?

Dr Dwyer: Yes, I do.

THE CHAIR: Before we get started with questions from the committee, do you have a brief opening statement you would like to make or are you happy just to—

Dr Dwyer: Yes, if the committee would not mind. I think it is important that, when looking at subjects like these that are inherently emotional, we look at them from three points of view. There is firstly the emotional. And nobody likes to see suffering. We sometimes fail to distinguish between our suffering and the suffering of the person we are looking at. The second is, I think, the practical. As a practising lawyer I do see children abusing their parents and wanting their money. I am involved in a case in that department at the moment. And there are people that are anxious to get their inheritances.

We also have to think, at the end of it, finally, about jurisprudence—about principle—and we have to weigh these things up. I did set out in my submission—I started from purely an abstract point of principle—that if you are working on the assumption that people have an absolute right in their own bodies and their own selves and they can do away with themselves, then what is the logical basis for prohibiting voluntary sale of oneself into slavery. We have been there before in European history and it is well worth thinking about.

I would like to start with the emotional. It is interesting that before I was 25 I had seen about half a dozen people die in front of me, which is unusual in this country. The reason was that we lived on the Pacific Highway in Sydney and my father was a doctor. There was a curve in the road, a very gentle curve, but in those days people would come home late and make mistakes.

I remember one occasion when a Mercedes went into a telegraph pole. I heard a crash. I got my father out. We had to go and see. The fellow was breathing but Dad just sort of shook his head, no chance. Another time a Volkswagen came around the corner, must have done something or other, overturned and there was blood 30 feet by 10 feet wide on the road.

When you have heard the death rattle at a young age it impresses you. I did not really think about this growing up. You would hear a crash. You would wake up. You would drag Dad out of bed because he was a doctor and you would go and see it. And it impresses you that there are some things that are outside your control. We are not the masters of our own fate. We are in the hands of providence, God, whatever you call it. You learn a respect, it is, for death.

Another time I was catching the train to university and there was a bump. I went up and under the wheel of the train I saw a bone, stripped down, and the wheel of the train had gone over it. These things impress you. They leave you with a real shock.

Thinking back, it comes back to me.

The other times I have seen death have been when I have seen my father die of cancer. My mother died recently at 93 of an obstruction to the bowel. She could not eat or anything. Thank heavens it was clear cut medically and it did not leave any difficult questions about intervention. Even a 50-year-old would have had only a one-third chance of surviving. You see these things and it teaches you some degree of respect for what you cannot control.

The third time, I suppose, is my own near death. I got septicaemia from my prostate biopsy. I was lying there in the room, I thought it was just flu and told my wife to forget about it. She thought otherwise and dragged me off to Canberra Hospital and, after two hours, she said, “You’ve got to do something.” They took the medical tests. I was full of bacteria in the blood and they raced me over to a ward.

For the whole week I was there the whole world was just in my head. And you are just in this world of your own thoughts. I have had a near-death experience. That makes you not rush to conclude what other people are thinking. In fact, you find your whole universe becomes richer as you think about things. You meditate in a funny way. You look out a window as you open your eyes and that is your whole world. It is as simple as that.

From an emotional point of view I do well understand people wanting to relieve suffering. But I also think they have to be very careful not to indulge their own suffering, their distress of looking at other people. If one thinks about it, that then turns you back to the philosophical. And I think you are inevitably forced to a philosophical view of these things. As I say in my submission, if you are going to take a cold, logical view of this, where does it all stop? From a practical point of view as a lawyer, we do see abuses, as I have said.

In terms of principle I do not think there is necessarily a conflict between emotion and the law as it stands, because, after all, murder is the intentional killing of an innocent human being. A killing of an enemy soldier is legal. The hanging of felons was legal in this country until recently. I remember growing up when men were hanged and nobody really thought much about it. They thought, “If you go murdering people maybe you should hang.” As a lawyer I have no philosophical objection to the death penalty for criminals. And there are wicked people. We have seen atrocities of mass murders and so on.

My real problem is proof of intention and sanity, because I think a lot of people who kill are insane and the evidence can sometimes never be sure. From a practical point of view you cannot really correct a mistake after you hang someone and you have got it wrong.

Just as there are practical terms against having the death penalty, I think there are practical terms here against having some idea of assisted suicide. Who is going to be there to verify it? Who is going to be there to check the motives? As I say, people sometimes want to change their wills: “Dad, you’re obviously insane; it’s time we helped you on your way.” We have already seen abuses of this assisted suicide in the Netherlands and Belgium and so on. And I do not think anyone can say you are really going to have serious checks. On a more optimistic note, in fact people sometimes are confused.

To come back to the concept of murder, it is the intentional killing of a human being. If a doctor honestly feels that somebody needs more morphine or whatever to relieve their suffering and that has the effect of causing their system to give out, that is not murder under our existing law. In fact, doctors have a wide degree of discretion in exercising their honest judgement in relieving pain.

I do not think the problem of suffering is necessarily as severe with modern medicine as people think. I actually have an enduring power of attorney. I had a client who was sick. She had a fall. She broke her hip. She got a urinary tract infection. I would say Canberra Hospital is not brilliant at doing the basic nursing. That of course had complications et cetera and was a very serious thing. In the end she died.

I think one can have an awful lot of suffering which may have a side effect of hastening someone’s death. But it is not intended. When doctors talk about side effects I always say, “Side effects are to medicine what aftershocks are to the Christchurch earthquake,” something so horrible you would not want it unless you had something worse first. But that is the trouble with any form of medication: there will always be side effects. But if those side effects, such as death, are not sought, they are a by-product of trying to honestly alleviate suffering, I do not think you necessarily have a legal problem under the existing law.

MS CHEYNE: In your submission I think you talk about the concept of absolute self-ownership being the one determining factor in all these questions. How is that relevant? Does it come down to the fact that we are created by something else and that there is a power beyond us that should be choosing our death?

Dr Dwyer: I think it is really just a matter of logic. If you say somebody has the right to dispose of themselves as an absolute right then you have to accept the implications of that proposition as a matter of logic. If I have the right to kill myself, why do I not have the right to go and sell myself into slavery? Ancient civilisations took that view. In fact, the slavery was regarded as a mercy to a conquered enemy. You had either death to face or enslavement for the rest of your life. Which would you take? At least if you were enslaved there was a chance eventually the boss might like you and set you free or be kind to you as a house slave or something.

I think we have to realise that our legal system is based on certain propositions. And these propositions are ancient. They go back a long way, and they are all posited on the idea of a lawmaker. The modern idea is that laws are something we make up for ourselves. The older view in English law was that laws are something that are inherent in nature and there has always been a distinction in our legal system between what is the lex gentium and the mala prohibita and mala in se—in other words, things that are evil in themselves and things that are made evil by statute.

If you look at the history of the common law there have always been common threads running through it. One thing that is still universal is: thou shall not kill, which is of course why, in fact, we have things like war crimes and why people have actually been executed for conduct during war which was not sanctioned by the rules of war.

We all know about the Breaker Morant story and all that sort of thing, where you went shooting prisoners or stuff like that. The commandment that thou shall not kill is probably about the deepest thing in our legal system. This idea that we are a democracy and therefore law is whatever we dream up is absolute rubbish. Law is something inherent in the nature of things.

It is very interesting to look at economics, which was my first discipline and still is. The physiocrats who were the first economists saw economics as a system of natural law exchanges and a natural revenue for the crown. They actually thought the natural revenue for the crown was from the lands, which, by the way, is why I am so annoyed that the ACT government threw away leases in this town and renewed them for 60 years for bugger-all. They threw away a revenue base. It is, in my view, a criminal breach of trust.

What I am saying is that there are views—and it is an ancient view and I think a sensible view—that there are natural laws which govern us in all things we do. Whether you ascribe that natural law just to mere provenance, whether you ascribe it to a creator, an Allah or whatever, is your business. But in terms of western civilisation it has always been regarded as inherent in the law that there are some parts of it, a core, that are natural: “You shan’t lie.”

Suppose we said, “I’m an autonomous human being”—and you see this in idiot libertarians, and I call them that—“I can do what I like. If it suits me I will get a girl pregnant and dump her and it is her problem and I have got no responsibility.” You see this stuff on the internet. And this idea that I am autonomous, I am the master of myself, I can do what I like—this idea of law is anarchy. People are bound by law. As a lawyer, I believe in law, obviously. But I do not believe in statutes necessarily. I think a lot of statutes are idiotic.

I do believe there is a core of natural law flowing through the common law. In the 19th century there was the common law as the perfection of human wisdom. I think there is a lot of merit in that view, because people learn from experience. The common law represents principle married to experience. I think something that we should think about here is that if you say there are circumstances in which the intentional killing of a human being is permitted and you can assist in it, then you really have to say, “What really are we doing here?”

MRS DUNNE: You have taken a somewhat philosophical approach to that question. Over the course of public hearings we have had some foray into that. But I would also like to ask you from a jurisprudence point of view a question that I put to a number of people. It is in relation to the law as it stands in the ACT and also in relation to the law generally and its impact on human rights. I have two questions. I will ask them both and then I will let you answer them.

One is that the law, as it stands in the ACT, is governed by commonwealth law, which prohibits the ACT from making law in this space. We heard from a witness this morning who thought that that could be subject to challenge in the High Court, whereas the Human Rights Commissioner has taken the view that it is not subject to challenge in the High Court, and that it is clearly within the bounds of the constitution. That is one question.

The other question, which also comes from some evidence that was given by the Human Rights Commissioner, flows from some of the points that you made. Although there are rights charters, no rights are unbounded. The Human Rights Commissioner raised the question about whether a right to life encompassed a right to death and whether the right to life and the limitations on any right extended to a right to death. Another witness pointed out to us the views of the European Commissioner for Human Rights in the case of Pretty v United Kingdom, in which the European Court of Human Rights asserted that a right to life did not encompass a right to death.

So I ask you two things: firstly, as a lawyer, what is your view about the ACT law? More generally, what do you think rights law says about a right to choose death?

Dr Dwyer: Responding to the first question, in terms of constitutional validity, commonwealth law prevails. Commonwealth power over the territories is plenary. The High Court did not waste much time striking down the ACT's same-sex marriage legislation. Fundamentally, if there is a clear commonwealth law binding the territory—the territory is not a state—it is fully subject. Under, I think it is, clause 122 of the constitution, the commonwealth can do what it likes. The commonwealth parliament can do what it likes.

In fact, most of us voted against self-government. Most of us were quite happy with the department of the capital territory. This parliament could be abolished tomorrow and all its acts—its ordinances as we used to call them—reduced to ordinances and altered by a ministerial signature. There is no question of the competence and the constitutional validity of the commonwealth law. It would just be a waste of ACT taxpayers' money to even start to dispute the matter.

Turning to the question of whether the right to life encompasses a right to death, that is a very interesting question because it raises the sorts of philosophical points I have been raising. If you are claiming that I have a right to life and, therefore, I have a right to death, you are going back to this idea of absolute self-ownership. It is a sort of, I suppose, naive libertarianism—sort of like Ayn Rand's *Atlas Shrugged* and all that sort of thing: "I am the fully autonomous, self-individualised person."

Of course, the truth is that no man is an island, as John Donne said, and that we actually live in a society. No matter how autonomous someone is, they cannot exist without the assistance and support of others. We are all interdependent. That was actually Adam Smith's great insight into human beings and the way they work. We actually serve each other in our existence, but I will not go off on that. I just do not see that one can seriously argue that a right to life necessarily encompasses a right to death, because the argument for a right to life is that we are not created by self-creating. Therefore, why should you have a right to death?

I think the proposition, once you recognise that we are not self-created—I mean, I did not create myself. My mother and father didn't. In fact, I once upset my mother. No, I did not upset her, actually. I always thought I was her favourite. I was a good chap and so on. She just looked at me and said, "We did not want any of you. I just loved your dad." So that put me in my place. The point is that parents do not consciously sit down and say, "I will have a perfect child." In fact, this is one of the problems I have with some of the psychological attitudes of people who think they are going to get a perfect child. You do not; you get what you get. We have six kids and we are very happy with them, but they are all different.

THE CHAIR: I could argue that I am a perfect child.

Dr Dwyer: I mean, you get what you get—

MRS DUNNE: Thank you.

Dr Dwyer: and you do not control the process. You are not supreme in this matter.

MS LE COUTEUR: You talked earlier about elder abuse, which clearly is happening even now. We do not have the potential legislation. Can you think of ways that we could actually reduce the instance of elder abuse in general and in particular if there were legislation that would allow voluntary assisted dying?

Dr Dwyer: I can, actually. I would say that the Public Advocate is pretty damn useless. In the case I have, I approached them because I think the abuse by a particular person, who cannot be named due to legal proceedings, was because he had become a legal drug addict on prescription drugs, because of the need for pain relief or something. He had lost all judgement and whatever. He wanted to see if the Public Advocate could intervene. As far as I can see, they are much more interested in hounding little old ladies who are hoarders or whatever, kicking them out of their house and giving the house to the Public Trustee than they are in taking on a difficult thing with an apparently able-bodied adult son who may be ripping off his parents.

The other thing I would say is that if you look at the costs of going to court—court fees and so on—the costs to any elderly person suffering elder abuse are huge to try to rectify it. The laws are all there. This is my problem. The law is fine. There is nothing wrong with the law; it is the administration of it.

For example, I think it is absurd that we have GST on legal fees. Legal fees are a cost of enforcing the rights which are meant to be protected for you by the sovereign. Why should you pay a tax to get what the sovereign owes you, namely, justice? Yet if you go to court, you are spending $100,000 before you start. If the Public Advocate is not going to do anything in these cases, what choice have you got? You could go to the police and say, “This person is a menace to himself.” What would the police do? They would investigate, prosecute and throw somebody behind bars. Would that solve the problem? No, you would still have to go through the civil action. I do think that perhaps the Public Advocate should be more willing to act on complaints, investigate them and assist, because I think lawyers are faced with a difficult problem.

If somebody has done something wrong, if you could persuade them they have done something wrong, you could settle the matter with a deed of family arrangement for a few thousand dollars. If you cannot do that, you are going to be in court for $100,000 to $200,000. I do not like litigation. I am a lawyer. My view is that if you can keep people out of courts, that is your job.

MRS DUNNE: Following up on Ms Le Couteur’s question, you have spoken of a particular case of elder abuse. Do you see this regularly in your practice?

Dr Dwyer: Not that often. Talking about abuse, I had one client I can think of who probably lacked testamentary capacity because of insane delusions about her relatives. I would not make a will for her. I gently declined but she went off and found another law firm that probably wrote themselves in as executors on a hefty commission. One gets a bit cynical in one's old age.

THE CHAIR: But we even hear reported in the news that there are some residential aged-care facilities that also do not necessarily care as well as they could for our elderly family members.

Dr Dwyer: Yes.

THE CHAIR: So it is not necessarily just family.

Dr Dwyer: No, exactly. Basically, people who are frail and elderly, if they do not have solid and caring family members around them, are exposed. You get people selling products like reverse mortgages or something like that. I would say that in many cases they are not in a person's interests. But coming back to this question about death, it is very interesting to go through a near-death experience. I can recommend it. It teaches you a lot.

MRS DUNNE: I think I will pass on that.

MRS KIKKERT: Thank you, Dr Dwyer, for being here and sharing your testimony. Dr Dwyer, sometimes when people submit their submission they feel as though they have forgotten something and they want to add that in. Is there something that you want to add to your submission that you may have forgotten to add before?

Dr Dwyer: No, I do not think so. I think I have pretty much said it, in broad principles. But I do think that, before you get stampeded through misguided emotion into changing the law, you just have to remember that the law does acknowledge what is, in philosophical terms, called the principle of the double effect. If a doctor does give, for example, morphine and that has the unintended result that a person's system cannot cope anymore, if that is given for the purpose of relieving pain then that is not criminal under the existing law. The law does give a wide scope for honest clinical judgement.

What was not honest was Lord Dawson of Penn when he bumped off King George V and they arranged his death to meet the news bulletins. That was actually illegal. He got a peerage out of it for his services. But that is by the way. People did not find out about that until later.

In a way, part of the business about euthanasia comes from an English attitude to animals. I have sometimes thought that IVF is a bit like that. There is an English tradition of dealing with animals: you put them down; you treat them. I think sometimes that attitude flows across to human beings. There has always been a joke that Anglo-Saxon people care more about animals than they do about people, but that is a continental view, I suppose.

THE CHAIR: Finally, Dr Dwyer, it has been a very interesting session with you today, I must be honest. I particularly found your opening remarks interesting. My father saw a lot of death and we were involved in a lot of death as I was growing up. My father was a fireman, so through accidents, fire, suicides and all sorts of things, he saw everything. I myself personally have cancer, so every day I face a near-death experience, so to speak.

Dr Dwyer: I did find an experimental treatment for cancer which worked brilliantly. I spent $20,000 to avoid going to Canberra Hospital and went to this experimental clinic in Melbourne. It is not there anymore. It solved it beautifully.

THE CHAIR: I trust Canberra Hospital implicitly. They are wonderful carers.

Dr Dwyer: Anyway, there is a brilliant treatment. It is called photodynamic therapy. I recommend you have a look at it.

THE CHAIR: No, I am quite happy with the treatment I am receiving from Canberra Hospital. I did agree with what you said about tending to consider what is out there, what has happened, when you do face the end of your life or when you think you might be. I have absolutely no religious beliefs at all; nor does anyone in my family. But I still believe that it is a choice that I should be able to make myself. I know that the law does not support that, necessarily, although the law does now provide for there being no criminal effect for suicide if you do take your own life.

From a legal perspective, you spoke about the commonwealth and the constitution. The Human Rights Commissioner, in her evidence, said that she believes that there is a human rights violation by not allowing the territory to be able to make its own laws. You seem to have a slightly different view from that.

Dr Dwyer: Is she saying that the commonwealth constitution is somehow subject to some human rights legislation?

THE CHAIR: I do not know that she went that far. She just felt that it was—

MRS DUNNE: No. I think it was about the autonomy of ACT residents to have control over the legislation.

THE CHAIR: Yes, to have the right.

Dr Dwyer: I am sorry, but the Commonwealth of Australia Constitution Act creates this constitution under the Crown, and all the powers the territory has come from commonwealth legislation signed with the royal assent of the Governor-General.

THE CHAIR: But if we were a state we would have completely different rules.

Dr Dwyer: We are not. Full stop.

THE CHAIR: That is correct.

Dr Dwyer: We are 911 square miles carved out of my beloved home state of New South Wales.

MRS DUNNE: And we will never be a state.

Dr Dwyer: And you will never be a state.

MRS DUNNE: The Northern Territory, maybe, but we will never be.

Dr Dwyer: From a legal point of view I find it incomprehensible to even raise it. This is the trouble with a lot of bloody poorly educated lawyers these days.

THE CHAIR: Could we could keep the language to a parliamentary standard.

Dr Dwyer: Parliamentary, sorry. I am sorry. It is idiotic, if I can put it that way. Is that parliamentary?

THE CHAIR: Probably bordering. I would say it is bordering.

Dr Dwyer: Bordering.

THE CHAIR: I think we understand what you are trying to say.

Dr Dwyer: It is legally incompetent for a lawyer to even pretend for one second that some notion of subordinate human rights legislation or whatever prevails over the Commonwealth of Australia Constitution Act and the schedule attached thereto.

THE CHAIR: So you honestly do not believe, besides the constitution, just from a personal perspective, that the residents of the ACT have the right to make their own laws?

Dr Dwyer: The territory belongs to the people of the commonwealth. It was paid for and created by the federating states. We serve the people of the commonwealth in this territory. Basically I am a New South Welshman. I came here in the 1970s from Sydney. I never wanted to come to this place and I have always regarded it as an exile.

THE CHAIR: It shows, too, I think, Dr Dwyer.

Dr Dwyer: The point is that the territory was created to serve the commonwealth. As for the states, the states had that power because they had it during the period of legislation that gave New South Wales self-government, I think in about 1856. Victoria, I think, was a bit later, the Port Phillip district. The province of South Australia and Western Australia were self-governing colonies. They had plenary powers.

There is no comparison between the constitutional law of the states and the constitutional law of the territory. The constitutional law of the territory is the federal self-government act. The federal government, unlike the parliament of Westminster, has not surrendered its legislative authority over the ACT, and it never will and it never can because the land of the territory is vested in the commonwealth and always will be. That was put in, by the way, so that we would have a revenue base, but that is another story.

THE CHAIR: In your submission you note in point 1 that it is implicit in any euthanasia appraisal that a person has absolute ownership of himself. What about herself?

Dr Dwyer: I prefer the language I grew up with, which is the English of the 1950s. I am perfectly happy with it.

THE CHAIR: Does that mean that women do not have rights?

Dr Dwyer: No. It is the normal usage of the 1950s, when I went to school, which is to use the male pronoun to include all human beings.

THE CHAIR: Thank you very much.

Dr Dwyer: I just think it is simpler. It avoids problems. “Him or her” becomes very tedious.

THE CHAIR: Thank you very much for your time, Dr Dwyer.

If witnesses undertook to provide further information or took questions on notice, which I do not believe happened today, answers to these questions would be appreciated within two weeks from the date of receipt of the transcript.

Dr Dwyer, when available, a proof transcript will be forwarded to you, to provide an opportunity for you to check the transcript and suggest any corrections, if required.

The committee adjourned at 12.18 pm.