



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

Submission Number: 167

Date Authorised for Publication: 29/3/18


EAST BOWRAL NSW 2576

22 February, 2018

The Secretary, Select Committee on End of Life Choices in the ACT,
Legislative Assembly for the ACT
GPO Box 1020
CANBERRA ACT 2601

Dear Secretary,

I am a 60 year old retired accountant. There are two issues that I wish to address on the topic of "End of Life Choices":

- 1 - inappropriate medical treatment given to dementia sufferers; and
- 2 - the right to choose Medical Assistance in Dying.

Inappropriate Medical Treatment:

The following events took place in New South Wales, but I raise them with you because I want to ensure that the same thing does not occur in the A.C.T.

My mother was afflicted with Alzheimer's Disease in 2001 at the age of 75. She was admitted to a low care facility in 2009, when my father could no longer manage her care on his own. She was moved to a high care facility in 2011. She is still alive, but merely existing, at the age of 92.

The Aged Care Facility in Newcastle which is now caring for her has twice administered anti-biotics, prescribed by a doctor, when she had Bronchitis. After the first incident about 4 years ago, my family instructed the nurses to never administer anti-biotics to her again without first discussing it with a family member. We made it abundantly clear that we wanted nature to be given the opportunity to take its course at the first (and every) opportunity. We saw no point in keeping her alive with medical treatment when she had clearly expressed her wishes to us many years ago that she didn't want to live with dementia. The same Aged Care Facility again administered anti-biotics to my mother on Christmas Eve, 2016 without discussing it with me or any of my brothers. This was again on a doctor's prescription, even though my mother's medical file contained an instruction not to prescribe any life-extending treatment. The Aged Care Facility later told us that the doctor did not actually visit my mother, but had prescribed anti-biotics over the telephone. We were told that the casual nurses on duty, due to Christmas holidays by the regular staff, did not find the instruction in my mother's medical file. When my brother, who visited that morning and found her in bed with a respirator and on anti-biotics, he arranged to stop treatment. The nurse said she couldn't do that without talking to the doctor, but my brother then found the page buried in her medical file, which instructed that my mother not be given any life-extending medication. This incident at Christmas 2016 highlights two serious problems:

**SUBMISSION BY GEOFFREY WILLIAMS TO AUSTRALIAN CAPITAL TERRITORY LEGISLATIVE
ASSEMBLY'S SELECT COMMITTEE ON END OF LIFE CHOICES**

- the doctor should not have prescribed medication without visiting the patient and discussing treatment with her family; and
- the instruction in my mother's medical file, not to give life-extending treatment, should have been prominently placed so that it could not be missed.

I raised this incident by email with Professor Ken Hillman from the University of New South Wales and Liverpool Hospital, whom I'd met at a Dying With Dignity (NSW) meeting. He agreed that my mother should not have been given treatment, but did not think anything would be achieved by suing the Aged Care Facility and the Doctor for assault. He explained that he was about to publish a book about End of Life Care, and that the public debate arising from that book would probably be more effective than an isolated civil suit in respect of one dementia patient. I have since read his book: "A GOOD LIFE TO THE END - Taking control of our inevitable journey through ageing and death". It is an excellent book, and I recommend that you read it, if you haven't already, and indeed consider the book as evidence to the inquiry on important aspects of end-of-life choices. Unfortunately, there does not seem to have been as broad media coverage and community discussion of these issues following Dr Hillman's excellent book as I had hoped.

The right to choose Medical Assistance in Dying

In an ideal situation, dementia patients should be allowed access to self administered Medical Assistance In Dying during the period between the time their diagnosis is confirmed and the time when they lose their mental and legal capacity to rationally request it. This is the situation currently permissible in Belgium. However, I do realize that such a provision would be not be achievable within the current political climate and thinking of Australians. Elderly patients are going to continue committing suicide if dementia is excluded from Voluntary Assisted Dying legislation. I personally have an Advance Care Directive that states I do not wish to be spoon-fed or administered antibiotics that may prolong my life if I am diagnosed with dementia in the future, and would suggest that this be considered as a recommendation by the Committee.

I draw the attention of The Committee to a speech by Reverend The Honourable Fred Nile MLC NSW in the Legislative Council on 16 November 2017, during its debate on the Voluntary Assisted Dying Bill. I was extremely displeased with Reverend Nile because the incident he referred to in his speech was completely irrelevant to the bill being debated, and quite possibly improperly influenced other Legislative Councilors to vote against the bill. I have since written to him again, having written prior to the debate, analysing his comments and expressing my disappointment in the standard of his preparation for the debate. His reply to my first letter was dismissive, and he has not replied to this second letter. I attach it for your information, because I sincerely believe that he misled the NSW Parliament. I will be sending him a copy of this submission, after it is accepted and published by this Inquiry.

I believe that the law in the Australian Capital Territory (and the rest of Australia) needs to be changed to allow a medically assisted death to be one of the options in a dying

patient's own 'End of Life choices', ideally as an additional choice as part of good palliative care.

I cannot understand why a doctor can put a patient into a coma, as a last resort of palliative care, with the intention of relieving pain, but cannot provide a 'bolus' dose of the same medication to the same patient with the intention of ending suffering when the patient has requested / begged for medical assistance to die.

Currently in Australia, a doctor only has to state that the intention of providing terminal sedation is to relieve suffering, "making the patient comfortable", and death can be hastened and indeed is inevitable from starvation or dehydration, **even if that patient has not requested assistance to die.**

I can see no legal or ethical difference between Terminal Sedation and Voluntary Assisted Dying. The only difference is that Terminal Sedation is completely within the law, but much slower, as patients may have to suffer while the dosage is gradually increased to ensure that the dosage itself does not immediately end a patient's life. This is within the existing law, but sadistic! It would be much more compassionate and merciful to allow patients to request that their life be ended quickly and with dignity, while they are still lucid enough to say goodbye to family and friends.

The introduction of legislation to permit medical assistance in dying will not impose in any way upon the lives of those who oppose such legislation. It will not impact upon the lives of such alleged vulnerable people as the aged and disabled, unless they meet the criteria carefully established in any proposed legislation, and request assistance to die with dignity. However, any continued opposition to Voluntary Assisted Dying (VAD) legislation DOES impact mightily on the lives of those poor souls who desperately need the right to die in peace with dignity. Church leaders who are often the loudest opponents of VAD are more intent on adhering to their religious dogma, and less interested in showing love and compassion for the truly vulnerable in our society - those proportionately few terminally ill patients for whom palliative care does not ease the pain.

I respect the right of people to disagree with my point of view, and I politely request that opponents of VAD equally respect the genuinely-held opinions of the vast majority of voters, including the significant majority of those designating themselves as Christian, who support the introduction of VAD legislation.

Not to heed the wishes of the majority of Australian voters is, quite simply, UNDEMOCRATIC! The actions of Kevin Andrews and his supporters in overturning the democratically introduced Rights of the Terminally Ill Bill in the Northern Territory was, in my mind, one of the most despicably undemocratic actions in Australian history!

It is my mother's predicament which prompted me to become active in the political process to introduce VAD legislation. I am a member of Dying With Dignity (NSW), the Voluntary Euthanasia Party (NSW) and Christians Supporting Choice for Voluntary Euthanasia. I stood as a candidate for the Voluntary Euthanasia Party in the NSW

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Legislative Council elections in March, 2015. I represented Christians Supporting Choice for Voluntary Euthanasia at the Senate Inquiry into Senator Di Natale's Medical Services (Dying With Dignity) Exposure Draft Bill. Also attached is the Hansard transcript of the Senate Inquiry on 3 October, 2014. The transcript of my evidence on behalf of my father-in-law, Ian Wood, who is the National Co-ordinator, begins on page 34. I was accompanied on that day by Ms Shayne Higson, a former Voluntary Euthanasia Party candidate for both the Senate and the NSW Legislative Council, and currently the Vice President of Dying With Dignity (NSW).

Conclusion:

It does not seem fair that patients in a growing number of jurisdictions overseas, including Canada, are able to request medical assistance to die in strictly defined circumstances, but all Australians are currently denied the basic human right of choosing the manner of our own deaths. (As the Committee are aware, Victoria is now to be an exception, as with the passing of their Voluntary Assisted Dying Bill 2017, Victorians are going to have this right to choose in future.)

Recommendation:

The Select Committee of the Legislative Assembly of the Australian Capital Territory on 'End of Life Choices' provides the ideal opportunity for all political parties in the ACT to work together to introduce and then to enact compassionate legislation for the terminally and hopelessly ill patients in a second Australian jurisdiction.

Associated Recommendation

That the ACT Government lobby the Federal Government to overturn/repeal the "Andrews Bill" that prohibits Voluntary Assisted Dying Legislation in the Territories.

Yours faithfully,



Geoffrey Kerr Williams

Encl: 1. Letter dated 6 December, 2017 to Rev. The Honourable Fred Nile, MLC NSW;
2. Hansard transcript dated 3 October, 2014 of Senate Inquiry into Medical Services (Dying With Dignity) Exposure Draft Bill


EAST BOWRAL NSW 2576
6 December 2017

The Rev. The Hon. Fred Nile MLC
Parliament House, Macquarie Street
SYDNEY NSW 2000

Dear Sir,

Thank you for your reply dated 26 October to my previous letter in respect of the Voluntary Assisted Dying (VAD) Bill. I wish to comment further on this issue, particularly after witnessing your speech during the debate on the morning of 16 November.

I was in the Public Gallery for your speech, and was at first appalled by the emotive and factually incorrect approach you took. Subsequently, I felt sad that it has tarnished your dedicated political and personal life.

I have reviewed your speech and your letter to me, and make the following comments.

You started your speech by alleging that the proposers of the bill should have been honest and named their bill “the Medical Murder Bill”, immediately demonstrating your bias in the debate. Your description in those terms was extremely emotive, and simply incorrect!

It is not ‘Murder’ for a medical practitioner to accede to a request by a terminally ill patient, who is already about to die, to assist in avoiding unbearable pain and suffering at the end of their life. Nor is it ‘Suicide’ for a terminally ill patient to choose a peaceful and quick death, rather than an agonising, long death. VAD is not a choice between life and death, but a choice between two different ways of dying! You don’t seem to accept the fact that the only patients who will be requesting VAD are those whose death is imminent and inevitable, and who are not able to be kept adequately comfortable in the excellent Palliative Care hospices!

Having accused the proposers of the VAD Bill of being deceptive, you then immediately proceeded to relate a horror story, which you incorrectly stated came from Oregon, to justify your point of view. That story has been the subject of further public discussion, and you have publicly admitted that you were confused by an incident in The Netherlands. Rather than publicly apologise for accidentally referring to the case being in Oregon, you further compounded your reckless mistake by

suggesting that it was “Divine Intervention”. I am confident that God would not want any of His disciples to make false statements, even honest mistakes.

This incident demonstrates clearly to me that your attitude to VAD has clouded your judgment about what is acceptable Parliamentary behaviour. I expect that our Lawmakers should be familiar with the bills they are debating, but it was blatantly obvious from your speech that you were ignorant of the provisions of the VAD bill, which is based on the similar legislation in Oregon. If you had been familiar with the law in Oregon, you would have known that patients self-administer the substance which is going to relieve them from their ongoing torture. They are not injected by medical practitioners. The same procedures are in the VAD Bill that you were debating.

You should have realised that the story in your speech could not possibly have related to Oregon, but you are so emotionally opposed to the VAD Bill that you didn't care about the accuracy of your source. Your speech was thus recklessly untrue, not befitting a Member of the Legislative Council. It is quite possible that one of the other 'No' votes was inappropriately influenced by your speech.

Your explanation in the Press about the “Divine Intervention” demonstrates that you are not ashamed of making the mistake of misquoting the source of the story. Rather, it seems you are self-righteous, believing that only people who agree with you on this issue are correctly interpreting God's Will!

It might therefore surprise you to know that Lord Carey of Clifton, former Archbishop of Canterbury, is in favour of VAD legislation, and publicly spoke in favour of a similar bill introduced by Lord Falconer in the House of Lords in 2014. Another high-profile clergyman to support VAD is Archbishop Emeritus, Desmond Tutu. You are probably also unaware, or choose to ignore the fact, that Newspolls have been showing consistent majority support to the extent of 85%, including over 70% of Christians, including myself. You and other Church leaders definitely do not represent the attitudes of the majority of parishioners who attend your collective Churches.

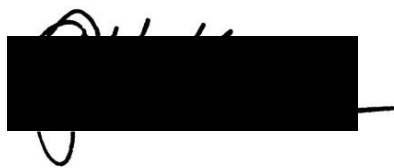
You say that you are a Christian Democrat, but your attitude on this Bill shows neither Christian compassion for the truly vulnerable - those terminally ill patients who are not being kept sufficiently comfortable in Palliative Care, nor Democratic principals. You don't care what the majority of the population (including Christians) want. You and the other opposing politicians treat Democracy with utter contempt on this issue! You are so determined in your 'crusade' against VAD that you ignore the facts about the successful operation of the VAD legislation in Oregon, and the fact that there is no so-called 'Slippery Slope'. Your determination seems to be based on the belief that VAD will be compulsory!

You said late in your speech that terminal sedation is not Voluntary Euthanasia, but I have trouble ethically distinguishing between the two. Patients can currently be put into terminal sedation (placed in a coma until they slowly dehydrate or starve to death over a period of weeks), even without their permission, and you think that is alright. But you do not think it is alright for a mentally competent, terminally ill patient to request the same outcome - immediate unconsciousness leading to a quick and painless death. The difference is pure semantics! The proposed VAD legislation would regulate the voluntary euthanasia that is already happening in some places, and would probably also ensure that patients are not put into terminal sedation without their permission, or the permission of their Enduring Guardians.

If you had gone to the trouble of studying the real experience in Oregon, you would find a paradox whereby some patients actually live LONGER after they have been prescribed the appropriate substance than they would have lived without it. About 40% of the patients in Oregon who are given a prescription don't actually use it! The powerfully palliative effect of knowing they are not going to suffer at the end of their lives removes a huge burden of worry, allowing them to make the most of their remaining time. By opposing VAD, you are actually going to shorten the lives of some terminally ill patients who are fearing a horrible death.

Instead, you related a case study which you incorrectly cited as being from Oregon. In so doing, you recklessly misrepresented the facts in a way that could easily have swayed the vote by other Members of the Legislative Council. As a result, truly vulnerable, terminally ill patients in New South Wales will still face a horrible end of life. Your behaviour was the antithesis of Christian Democracy, and you should be thoroughly ashamed of yourself.

Yours very sincerely,



Geoffrey Williams



COMMONWEALTH OF AUSTRALIA

Proof Committee Hansard

SENATE

LEGAL AND CONSTITUTIONAL AFFAIRS LEGISLATION
COMMITTEE

Medical Services (Dying with Dignity) Bill 2014

(Public)

FRIDAY, 3 OCTOBER 2014

CANBERRA

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SENATE

LEGAL AND CONSTITUTIONAL AFFAIRS LEGISLATION COMMITTEE

Friday, 3 October 2014

Members in attendance: Senators Di Natale, Ketter, Leyonhjelm, Ian Macdonald.

Terms of Reference for the Inquiry:

To inquire into and report on:

Medical Services (Dying with Dignity) Bill 2014

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ROOT, Ms Jo, National Policy Manager, COTA Australia**Committee met at 09:05.**

CHAIR (Senator Ian Macdonald): Welcome. I declare open this public hearing of the Senate Legal and Constitutional Affairs Legislation Committee inquiry into the Medical Services (Dying with Dignity) Exposure Draft Bill 2014. This bill is a private senator's bill, not a government bill. This is a public hearing and the proceedings are being broadcast live via the web. If anyone particularly wants to be heard in camera they should ask the committee and the committee will determine that request. All witnesses are reminded that in giving evidence to the committee they are protected by parliamentary privilege. It is unlawful for anyone to threaten or disadvantage a witness on account of the evidence being given to the committee and such action may be treated as a contempt. It is also a contempt to give false or misleading evidence to the committee. We prefer evidence to be given in public but, under Senate resolutions, witnesses to have the right to request to be heard in a private session. If that is the case, we would ask that the witnesses indicate that to us as soon as possible. If a witness objects to answering a question, they should state the ground for the objection and the committee will determine whether it will insist upon an answer. If the committee determines that it wants an answer, the witness may request that the answer be given in camera. When called to answer a question for the first time a witness should state their full name and the capacity in which they appear. Witnesses should speak clearly into the microphone to assist Hansard to record the proceedings. We would ask you to stay behind for a little while after you have given your evidence just in case Hansard needs to clarify any terms or references that you make.

We have received a submission from COTA Australia, which we have numbered 14. Unless you first wish to make any amendments or alterations to your submission, I now invite you to make a brief opening statement after which the committee will ask you some questions.

Ms Root: I thank the committee for the opportunity to appear. COTA Australia is the national policy arm of the COTAs. COTA is a federation. We have eight state and territory COTAs. We have got around 35,000 individual members and 1,000 organisational members. So our latest estimate is that we represent about half a million people. I think that is important for this committee. Our members are not a homogenous group. They come from a wide variety of backgrounds, cultures and beliefs and there are a wide variety of views on the subject being discussed here today.

Currently COTA Australia and all the COTAs take a neutral position on voluntary euthanasia. That means we accept the current status quo—that is, that it is not legal anywhere in Australia—and we are not agitating for a change in that legal status. We have had many debates about this across the movement. In my five years with COTA we have discussed it three times at our national policy council. There are people who argue for a change and people who argue against a change, and they are all committed and very passionate about their particular positions. We have decided that it is a matter of personal conscience for COTA members, and they can pursue their passions with other organisations if they want to advance the case in any way. For our submission, we did seek the views of our members, through our state policy council, so some of their views are reflected in our submission. We framed our submission not in terms of supporting the proposed legislation but, rather, by saying: if we were to legalise voluntary euthanasia, what should the legislation look like to provide the right protections for individuals and health professionals but give those who want to use it access in an equitable way?

I guess our first concern is with the title of the legislation. We believe everyone has the right to die with dignity—as far as possible, in the place of their choosing and with their cultural and religious beliefs respected. We feel that using the term 'dying with dignity' in the title of this bill undermines the significant progress that has been made on promoting that belief. It seems to be saying that the only way to die with dignity is to have someone help hasten your death. This certainly came up in the feedback from all the COTAs as an issue for people, even those who perhaps have a less than neutral position on voluntary euthanasia. We know that this is not the intention of the legislation, and we think changing the title to something like the recently proposed Tasmanian legislation, which used 'voluntary assisted dying' in its title, would be helpful in the discussion.

Our other key concern is around equitable access particularly for people who live outside the metropolitan areas of Australia. The requirement to have a number of medical practitioners who are not in the same practice and who are not in any way connected to each other through their practice, and also access to a psychiatrist, could significantly limit access to the services being described in the legislation for people living in rural and remote areas. We think it could encourage people to seek their treatment in hospital, where they would be able to access a number of practitioners, and that would seem to run contrary to the view that we have seen yet again with the recent report from the Grattan Institute that 70 per cent of people want to die at home—and yet most people do not. So we think that, if this legislation is going to facilitate choice and access, we would need to have a look at what it does for rural and remote people.

CHAIR: Thank you. Do any of your state bodies have a fixed policy position on this question?

Ms Root: No. We all have the same neutral position at the moment.

Senator KETTER: I note that you framed that neutral position as one of not seeking to change the current legislation.

Ms Root: Yes.

Senator KETTER: That would tend to indicate that your organisation is comfortable with the current legislation.

Ms Root: No. I do not think you should interpret our position in that way. We have this discussion all the time in COTA. We used to say we did not have a position at all. But it was said to us that we had to have a position. So we tend to take the position that the current legal situation for many things in Australia we do not contest. We are not looking to change. I think it is more that we really are accepting that that is the legal position. We are very happy to enter into discussion. Recently many of the COTAs have been running forums about end of life care, palliative care, and they have been incorporating the issue of assisted dying in their discussions. We are happy to be part of the conversation and we think it is a conversation that needs to happen.

Senator KETTER: I want to go to your comment on the definition of illness under the bill. The definition includes 'degeneration of mental faculties'. You say you think that definition needs clarifying. Could you amplify that comment a bit?

Ms Root: We are happy that an illness that includes degeneration of mental faculties should be included in the scope of any such bill—because obviously we have people with dementia and other degenerative diseases that impair their mental faculties. I guess it is an issue of timing. The bill goes on to say that you have to be of sound mind and competent at the time of making the request. That seems to be a little bit at odds. We are not talking about people having an advance health directive that includes involuntary euthanasia—'In case I lose my mental faculties I want X'—you have to actually be in the situation at the time. We think that is something that needs teasing out and perhaps discussion with people better qualified than me to think of how we might get around that. But we are just flagging that is an issue.

Senator KETTER: You have mentioned dementia. Alzheimer's is considered to be the disease of the century and poised to have a near-catastrophic impact on the world's healthcare systems. I presume that, among the ageing, this is seen as a concern for people.

Ms Root: Yes.

Senator KETTER: Are you familiar with the work of Professor Megan-Jane Johnstone, of Deakin University, who last year talked about media representations of Alzheimer's and how that has impacted on people's perceptions of euthanasia?

Ms Root: Yes, I am familiar with it. I know that Alzheimer's Australia has its own position on voluntary euthanasia for people with dementia. My understanding is that they take a similar position to us. But I am not going to speak for them. I do not know whether they put a submission to you and I am not aware whether they are appearing before the committee. Many people are frightened of Alzheimer's; that does come through. It is not actually one of the issues that comes through when we have had discussions with people about voluntary euthanasia. Alzheimer's is not one of the illnesses they often articulate to us. It may be that it is behind it. People often articulate diseases where they think they are going to be in incredible pain. One that comes up all the time is motor neurone disease. Anyone who has witnessed someone dying from motor neurone disease will know that it is one of the more difficult deaths to watch and it is difficult to give someone a good death when they have motor neurone disease. So people often talk about those sorts of things and conditions that are not amenable to palliative care. When Minister Butler did his conversations with older people around aged care voluntary euthanasia came up in nearly every conversation. But it was not in the context of the whole of dementia. But people are certainly frightened of dementia. That raises the issue about when people make the choice—do you do it at the point of diagnosis? Alzheimer's Australia would say you could still have a good 10 years of very good quality life. It does not come up as an issue; that is all I can say.

Senator KETTER: Are you familiar with the experience in Holland with voluntary euthanasia?

Ms Root: I have read a bit about it, yes.

Senator KETTER: In your submission you talk about equity of access to facilities. My understanding is that in Holland the right-to-die societies formed a network of travelling euthanasia doctors.

Ms Root: Yes, that is true. I think in Holland it might be easier because the distances are shorter and the population is denser. If you had similar legislation here you would get a network of doctors who at least speak to

each other and support each other in that process. I note that the bill, quite rightly, gives health professionals the right to say no. I think that is one of the critical conditions. If it is about personal conscience it is about the conscience of the health professional as well as the conscience of the person who is asking for their death to be assisted.

Senator KETTER: Are you familiar with the types of cases that are reported in Holland as to the people who are now utilising euthanasia?

Ms Root: No, I have not looked at it recently.

Senator KETTER: I do not have the formal statistics in front of me. But would it surprise you to know that there is an increasing number of people who are accessing these services who are aged, lonely or bereaved?

CHAIR: I might make that your last question, Senator Ketter, so that we can share the time fairly. I again remind my colleagues that Ms Root is doing a very good job at being entirely neutral. I am sure you have an opinion, Ms Root—I am not going to ask it what it is, and I will not let anyone else ask you—but you are doing a fabulous job of running the neutral line. If Senator Ketter's question requires you to enter into a debate which you do not want to enter, feel free to avoid it.

Ms Root: No, I think it is a good question. I think it is possibly one of the concerns for people that the bill before us is very clearly about people who have a terminal illness and are asking for their death to be assisted. I think the whole issue around why people might be lonely and depressed and whether they have a mental illness is something that needs much more exploration. We probably would say that we need better services to help people and we need to address the issue of social isolation in older people—particularly people with Alzheimer's. Alzheimer's Australia released a report just last week talking about the stigma and social isolation of people with dementia. So there are a whole range of other things in society that we need to address that are not really part of this bill.

Senator DI NATALE: I would like to put it on the record from the outset that this bill is an exposure draft. That is unusual. Most bills that come before committees like this are draft legislation where there may be some minor changes and issues that have not been identified that need to be addressed. But this is an exposure draft, meaning that it is a starting point; and the end point for this legislation may be significantly different from what is being proposed at the moment—and that is the purpose of today's hearing. I am interested in the discussion—I am sure it is a very active discussion, and you touched on it—around palliative care, advance care directives and assisted dying. Some people will argue that palliative care, if it is done well, means there is effectively no need for assisted dying—if we can do palliative care better, it becomes a non-issue. That is according to some of your members—and I understand that it is controversial. Would that be the view of all your members? I do not think there is any disagreement that we need to do much better when it comes to palliative care and advance care directives. But would some of your members still see a role for assisted dying even if we were to improve those areas?

Ms Root: Possibly one of our concerns about the way the bill is drafted—we touch on it in our submission and I think it is relevant to your question—is the whole issue about quality of life. That is often a very subjective thing—what one person might like their life to be can be quite different from what another person might like their life to be. Palliative care—I am not an expert, although I have done some work in the area—can give pain relief and do all sorts of things. But I think it is a very personal decision—and that is a view put forward by many of our members. The view we would have is that we do not see them as mutually exclusive. We got the National Palliative Care Strategy after the Andrews bill on voluntary euthanasia in the Northern Territory. It was seen as one thing we really needed to start addressing, and I think that is true. We would also say that we need to address the whole issue of advance health directives and have more people having advance health directives. But I think it can coexist.

Senator DI NATALE: Tell me a little more about some of the concerns people raised around access?

Ms Root: If you live in a country area and the one GP there does not want to do it, how do you find somebody? There is no requirement in the bill—and I am not sure whether there should be—to refer somebody to a doctor who will do it. I know that for some other medical services there is a view that, if you do not want to perform a particular procedure for your own cultural or religious reasons, you are really obliged to help somebody find a doctor who will do it for you.

Senator DI NATALE: We are specifically talking about terminations?

Ms Root: Yes.

Senator DI NATALE: That is the obvious one. So if you are not prepared to offer somebody a referral for a termination, you need to refer them to a GP who will do that for the patient?

Ms Root: Yes. I guess the other side of that is that there are a number of organisations—Dying With Dignity, voluntary euthanasia societies and others—who would help people find a medical practitioner who would help them. I am not sure we should leave it to that kind of network. It came up mainly in the context of getting a medical professional who is prepared to do it—and, in rural areas, having one doctor and then having a second doctor to confirm that and then having access to a psychiatrist and then possibly having access to a fourth medical practitioner who is a palliative care specialist because none of the others have got that or the first one did not have enough expertise in that area. For those of us who have spent time in rural Queensland, there is one GP, if you are lucky, and that might not be in your town. It is about how you access these multi-layered health professionals to help you get to the decision. People understand the reason for that. It was just raised as an issue where, if we are going to have it, let's make sure it is available to everybody on fairly equal terms.

Senator DI NATALE: That has been raised with me privately. Do you have any suggestions about how we can address people's concerns about an individual GP and having a second opinion versus access? Do you think a psychiatrist should be involved?

Ms Root: We put in our submission that we wonder whether just having a one-off session with a psychiatrist who has never had the patient before is actually an appropriate mechanism. We think there definitely needs to be an assessment of the state of the person's mental health at the time they are asking. We are not health professionals but we think there may be GPs who have competence in that area who could be seen. Also, if the first medical practitioner is the doctor that the person has been seeing for a long time, they may be able to give an assessment of the person's mental health.

Senator DI NATALE: Do you have any other specific concerns about the bill that you would like to outline?

Ms Root: We are concerned about clause 17, which gives the secretary the right to refuse a claim for providing the services. If the paperwork has all been done and all the listed criteria have been met, we do not see why there should be discretion for the secretary to disallow a payment. And once you start getting into disallowing payments, you can start inequitable access because people would then be concerned about who would pay for it.

The other concern, which has been raised with us by a few people, is the role of the family in any discussion. I think you could view it as a very personal decision to have somebody hasten your death—and whether family could overrule it, in the way that they can overrule organ donation, was raised with us by a number of people. We did not go into it in too much detail, but it was certainly raised with us that, if you had it in place, could family members intervene in some way and whether we want to consider making it more explicit that that could or could not happen depending on which way it wanted to go.

Senator DI NATALE: Did your members have a particular view on that? Was there consensus among those who supported the legislation?

Ms Root: There is a consensus in our organisation that families should not have the right to overrule organ donation where a person has specifically said that they want to be an organ donor and has gone on the register and done everything. I guess it is about respecting people's wishes when they die regardless of whether you are assisting them to die or not. I mean, we want to make sure that advance health directives are enacted and that families cannot overrule those—and we would see this as being in the same sphere.

Senator DI NATALE: What about the role of independent oversight? This perhaps goes to one of the questions that you were talking about previously. Do you think there needs to be some independent oversight? Who would do it? I understand your concerns about the state being involved in these personal decisions. Do you have any views on that?

Ms Root: We did not really discuss that at COTA, so COTA does not have a position on that.

CHAIR: Has your organisation ever contemplated having a ballot among your members, not to actually form a policy but just to get an idea of what your members feel about it?

Ms Root: We have had discussion about that. If we were to do such a ballot, it would be state-by-state because of the way our organisation is designed. People actually join their state's COTA, and the only members of COTA Australia are the eight state members. Some of the states have discussed it. There are certain issues even in asking the question, as you would appreciate. What do you do with the answer? If 80 per cent of the people who respond want you to support it, do we change our position and say we support it? And then what happens to the other 20 per cent? It is something that people feel very strongly about on the whole. In a room of COTA members, you probably would not get many people sitting on the fence on it. We have seen surveys that say that 80 per cent of the population are in favour of voluntary euthanasia in principle. That may well be true, but we have not yet tested

it. We talk about it quite often. I have been trying to encourage one of the states to do it just to see what would happen. But, so far, nobody has actually done it.

CHAIR: Perhaps it could be a survey just for interest's sake rather than to formulate the policy of your organisation. Anyhow, that is not for me to do—although I could well join your organisation! Ms Root, thank you very much and, again, congratulations; you got through that in a very balanced way, and it is sometimes not easy to do that. Thank you very much for your evidence. We very much appreciate it.

BOESEN, Mr Michael Thomas, Convenor, 9 Concerned Citizens

MARCH, Dr Milton Edgar, Member, 9 Concerned Citizens

[09:35]

CHAIR: Thank you very much for joining us today. I think you were both in the room when I read my obligatory list of conditions and what you can and cannot do, so I will not repeat that. We have your submission—No. 12. If you would like to make any amendments or alterations to your submission, you are able to do that now. I invite you to make a brief opening statement, and then we will ask you some questions.

Mr Boesen: I will start. As a group we strongly support the draft bill's intention that end-of-life medical services be made available to mentally competent adults who are suffering from terminal illness. We congratulate the proponents on this initiative. The provision of those sorts of services would be appropriate, we think, in view of the attitudes expressed in numerous surveys. The consistently indicate that at least three-quarters of the population would support such provision.

However, we feel that, while the majority of people who would qualify for those services would have a terminal illness, we believe that there are others who also should have such access rights. Specifically we think that such services should be available to mentally competent adults who are experiencing pain, suffering, distress or indignity to an intolerable extent irrespective of whether or not they have a terminal illness and whether or not their illness is curable. We feel that the bill's requirements that an evaluation be made by two medical practitioners plus a psychiatrist is unnecessarily complicated and could lead to restricting rightful access to the medical services in, for example, country regions. We think that an evaluation by two doctors, one having psychiatric training, is sufficient.

Excluding a person from the end-of-life service solely because they have what is referred to in the bill as a 'treatable clinical depression' is inappropriate in our view. That term is not defined. I do not know if there is a standard medical definition of it, but it is not defined in the bill as far as we can see. Some people may find initial or continuing treatment for depression intolerable. So exclusion because of depression might be unreasonable in many cases. For example, if a person has multiple medical conditions that lead to an intolerable quality of life, understandably they would be depressed; you would not be happy about that at all. But that should not preclude them from access to the medical service.

Palliative care appears to be given inappropriate prominence through section 13(3). While palliative care meets many people's needs and serves them well, some people on the other hand would regard it as intolerable and not a service that they would want.

There are two important sets of suggestions that we make for changes to wording of the bill. To broaden its coverage, the most important of the suggestions is changing the precondition specified in section 12(1)(c) to this: the medical practitioner is satisfied on reasonable grounds that (1) the person has a medical condition in respect of which he or she is experiencing pain, suffering, distress or indignity to an extent that is unacceptable to them and/or is suffering from a terminal illness—that would broaden it so that it is not confined to people who have a terminal illness—(2) there is no medical treatment that is acceptable to the person as a remedy or cure for the medical condition and/or terminal illness; (3) the only medical treatment that is acceptable to the patient in respect of their medical condition or terminal illness is treatment that will lead to a dignified, painless and comfortable death; and (4) the patient's reasons for rejecting any other medical treatment comprise a rational, considered evaluation. This point of rationality we think is a most important point. The patient must therefore be mentally competent.

The other set of suggestions relates to this aspect of treatable clinical depression, and our proposed wording for that would be, in section 12(1)(e): a second medical practitioner who has qualifications in psychiatry has determined that (1) the patient does not have treatable clinical depression—and that needs defining—(2) the patient has depression but there is no treatment for that condition that is acceptable to the patient; and (3) in the case of the previous paragraph the patient understands fully the nature of their depression and the options that are available for treatment, their reasons for rejecting such options comprise a rational, considered evaluation, he or she is able to make a rational, considered decision about the consequences of not commencing treatment or of ceasing treatment and he or she is mentally competent.

That is the end of our suggestions. It is pleasing to note, however, that the suggestions we make are reflected in many of the submissions, for example 3, 13, 32, 42, 52, 81, 89, 94, 101, 102 and 127. We thank you for the opportunity to put forward our views. While we are a small group and it was cobbled together very quickly once we knew of the ability to put in a submission, we are inclined to believe that there are many people like those in

our group who would endorse what we have said. Thank you very much for this opportunity, and thank you, Senator Di Natale, for the draft bill.

CHAIR: Thanks very much. Dr March, did you want to add anything?

Dr March: Very briefly. First, I should make it clear that my doctorate is not in medicine.

CHAIR: I was going to ask you that.

Dr March: I thought that should be made clear. Basically, the reason we have come together is that we think this bill is a thrust in the direction which the general population wants to make. People should be allowed to make a choice about their end of life, and it should be their choice mainly. There must be safeguards; we understand that. There are conditions which should be met and, perhaps, if a person is of rational mind and—we specifically are, as you might judge, from the mature end of the field. Having seen my mother at the age of 101 lying with a fractured femur and being shuffled from hospitals to repatriation areas to nursing homes when all she kept saying to me was simply, 'Why can't I just die? Why can't I just die?' I have personal feelings in that area, but this is the submission that we brought as a group. It should be possible for a person nearing the end of their life to make that decision, and it should be basically their decision alone.

Some of the clauses in the bill we think seem to be trying to prevent the making of that decision rather than facilitating the making of the decision by a person who is of competent mind and understands the situation but is in unbearable suffering through either injury, illness or some other matter.

CHAIR: Thanks very much. You heard the previous witness and have as well raised the problems for people living in more remote areas. Do you think the suggestions you make to improve the bill address that issue? Do you have any thoughts on how you could address the remote living issue?

Mr Boesen: In a word, no. Perhaps reducing the number of medical people involved from three to two would make it easier. Going to two doctors plus a psychiatrist and the requirement that there be somebody in there with palliative care knowledge just makes it so difficult. It just seems overly cumbersome. If you could get two doctors who agree, one of whom has psychiatric experience, I think that would be sufficient. In our view, you need to determine their rationality, and that should not be a big problem for two doctors.

CHAIR: Okay, thank you very much. I will pass to Senator Di Natale.

Senator DI NATALE: Thank you very much for your submission. As you are aware, this is an exposure draft of the bill and very open to the suggestions you and others have made. This really is the starting point rather than the end point. I suspect there will be people who, regardless of the changes that are made, will oppose it and there will be others who will support anything that comes forward, but we are trying to develop legislation that we think really balances the tension between having safeguards and making it accessible to people who need it.

Let me ask you about the issue of restricting it to people with a terminal illness. The counterargument that is often made is where you stop. At what point is a decision for somebody to take their own life a rational one and at what point do we make a decision that it is now unacceptable? Perhaps it is worth exploring what some of the conditions that may not be terminal illnesses but you are reflecting on might be so we can get a sense of who would be unable to access the legislation in the form it is currently drafted.

Mr Boesen: The expression 'where does it stop' worries me. I would look at it from the point of view of meeting the needs of specific people. This is not necessarily the view of the whole group. I think it would be, but I cannot predict it. In my view, when people get to the age of 70 or 75, many of them are suffering from multiple illnesses and many of them get to the point where they would want out. The trick is to say, okay, if we have such people in the community—and I think there are many surveys which would prove that that is the case—how do we satisfy those people's needs without risking other things? Let's solve their needs. The bill does not solve what I see as being my needs, or the needs of our group. So, my question to you is: are you going to look after our needs? You can build in all sorts of safeguards, as is demonstrated in all those jurisdictions that have implemented voluntary euthanasia, or physician assisted suicide. They have the safeguards built in. My point is to look at what the needs are and to satisfy those needs.

Senator DI NATALE: But in doing that the legislation may also allow a 60-year-old person—and, again, we are just teasing this out—with rheumatoid arthritis, who is finding it difficult—

Mr Boesen: How old?

Senator DI NATALE: Let's just say someone at that age of 60 who has severe rheumatoid arthritis and who, according to the definition you suggested, is in significant suffering, and there is no cure for that condition, and in their view the treatments that are available—and some of the treatments for rheumatoid arthritis have significant

side-effects—so they make a rational decision to exercise their right to voluntary assisted dying. In your view, is that a need that needs to be satisfied?

Mr Boesen: Why not?

Senator DI NATALE: I am asking a question.

Mr Boesen: Yes, it should be satisfied. It is their choice. If they are fully cognisant of what the options are, what the available treatments are, what the downsides of those treatments are, what will happen if they do not use those treatments, and if they have made a rational, considered decision that that is their choice, my view is you should not stop it.

Dr March: I would agree with the thrust of that. The basic point about the submission is that if a person is in a situation where life is unbearable for them, they are the ones who are the important ones to be making the decision. We are looking for the sort of bill that does not put blocks against them being able to be treated in a way that respects their own cognitive ability and their own decision to analyse a situation and make a decision and say, 'I am sorry. Farewell. This is what I want.'

Senator DI NATALE: To tease that out further, take a 40-year-old with ulcerative colitis, which is a medical condition that again requires immunotherapies, has nasty side-effects and so on. At the age of 40 they make a decision that they do not want to continue the life they are leading. Without the medication they have serious symptoms. Again, do you think that is a need that should be dealt with through this legislation?

Mr Boesen: Why should it not be met?

Senator DI NATALE: I am just interested in teasing it out. Some people would argue that that is perhaps taking the issue into an area that some people are not comfortable with.

Mr Boesen: Yes, I appreciate that.

Dr March: There are cut-off limits that you could keep pushing and pushing.

Senator DI NATALE: I am trying to tease out if you think there should be a cut-off. Ultimately, is it the right of an individual of sound mind to decide to end their life at any stage, should they wish?

Mr Boesen: My personal view is that there should not be a cut-off point.

Dr March: I would probably support that situation. When you are taking it to extremes like that it is difficult. That is the argument we hear of the slippery slope et cetera, which, as far as I am aware, has not been demonstrated in any of the areas where this sort of legislation has been introduced. We are assuming that the person making the decision is a normal, rational individual. The main objective should be to try to consider that person's point of view rather than trying to place blocks and blocks against them acting in that capacity.

Senator DI NATALE: This is always a balancing act.

Dr March: It is indeed. I acknowledge that.

Senator DI NATALE: Let me ask you about the issue of depression. Your concerns are that if somebody has a terminal illness and they are depressed, that is actually a normal reaction to that terminal illness and they should not be restricted from treatment. Do you think they should at least undergo some form of treatment, because some people with depression in response to a terminal illness can begin a course of anti-depressant medication and in fact their depression improves, and they may in fact make a different decision under those circumstances? So why do you suggest the change that you have in your submission?

Dr March: I do not think we suggested that change. We have suggested that it would be unnatural if a person in this condition did not have some form of depression.

Senator DI NATALE: Yes.

Dr March: Whether or not that is treatable—I do not know what the definition of treatable is. But if that person is aware of the consequences of their decision, and they are aware that it may be possible to offer them a treatment and it may be possible to give them a chance to change their mind, which is possible, it should not be a necessary blocking condition—that is, that because they are diagnosed as being depressed they are blocked from using this particular legislation.

Senator DI NATALE: Your primary concern is that someone with depression should not be denied access, simply because it can be a normal reaction?

Dr March: Yes. I know that as I get older and parts keep on falling off—for example, I spent last weekend in Calvary Hospital—I know that I am going to develop conditions and I am going to end up in a pretty bad mood, but I do not want that to be a block to my access to that sort of service.

Senator DI NATALE: I think that is a reasonable point. The last issue is that of medical practitioners. In your view, to summarise, you do not believe there is a need for a psychiatrist, you think it is reasonable to have two GPs, but you do not think there needs to be demonstrated expertise in the area of palliative care?

Mr Boesen: No—

Senator DI NATALE: As a requirement.

Mr Boesen: Correct. If I could elaborate a little bit, we are not knocking palliative care. It is available. They put out a terrific service that meets the needs of many people. But there are other people who do not want palliative care. We do not want palliative care. We do not feel that the people evaluating our needs need to have such a specialisation.

Senator KETTER: If I could continue on with the point Senator Di Natale was exploring regarding the limits of the access to voluntary euthanasia. You have said in your submission that it should be available to people 'experiencing pain, suffering, distress or indignity to an extent unacceptable to the person'. I take it that each of those four criteria is mutually exclusive, in the sense that, if somebody is experiencing a situation of indignity that is intolerable to them but they are not necessarily in pain, is that a situation in which you would agree with voluntary euthanasia?

Dr March: They are, to the extent that if somebody might be so inconvenienced by having basic bodily functions that are unworkable and causing indignity and embarrassment to them and they do not want to persist in that situation, we think they should be given the same right of access to this sort of thing.

Senator KETTER: Perhaps I will put a situation to you, Dr March, of an elderly person who feels that they are a burden on their family. That is an undignified position from their perspective. Does it meet your test of being unacceptable to that individual in the criteria you have set out here? Would you agree that a person in that situation should have access to voluntary euthanasia?

Mr Boesen: Correct me if I am wrong, but when we are talking about indignity we are talking in terms of situations where one's toileting and feeding has to be undertaken by another person and you are locked into bed and cannot get out, so your needs are being met by another person. They wash you, feed you and clean you. A person in that situation is suffering from indignity. I do not think the group would say we are talking about somebody you have just described—an old person who feels they are a burden on others. No, we are not thinking in those terms.

Dr March: If I could add to that, I do not think the word indignity includes this feeling of being a burden on somebody else.

Senator KETTER: According to your view, it is up to the individual to decide that, isn't it?

Mr Boesen: We will define indignity for you. It is in the terms I have described.

Senator KETTER: So there has to be a medical condition?

Mr Boesen: That is what it says. It says that the person has a medical condition.

Senator KETTER: The submission then goes on to talk about the fact that depression is one of the conditions that are excluded from that.

Mr Boesen: No, not from that change. It states, 'the medical practitioner is satisfied on reasonable grounds that,' and then lists certain things. I do not recall we mentioned depression in there. The patient certainly has to be mentally competent and capable of rational decision-making.

Senator KETTER: So any medical condition that causes a person to feel that they are not living in dignity is acceptable?

Mr Boesen: No, it is undignified to them. They are in an undignified environment and situation. The sort of situations we had in mind was where somebody needs other people's help all the time to move, to eat, to clean and to sleep. There are many of those people, and they are going to increase in number as the population ages.

Dr March: To take the point further, the situation is not the inconvenience to the other person. We are emphasising here the inconvenience to the person who is receiving the treatment—the indignity to that person. We are not pressing about the fact that your younger brother might feel a bit guilty about helping you. We are pressing about the fact that the person himself or herself may be in the situation that I mentioned my mother was in. She was in a terrible situation suffering great pain from fractured femurs and things, and being made to lie in a bed and take her time to die.

Senator KETTER: I take you back to your suggested change to section 12(1)(c)(i). You state:

... the person has a medical condition in respect of which he or she is experiencing pain, suffering, distress or indignity to an extent that is unacceptable to them ...

I put it to you that it may weigh on that person's mind that it is unacceptable to them that they are a burden on other people—their family.

Dr March: That is possible. Everybody worries about the burden they are causing to other people. Not everybody. I will admit that some people enjoy it. There are patients and nurses in the world—people who are born to help other people and people who are born to be helped by other people. Not everybody feels indignity at being helped. But if a person is in a situation and they do not want to persist with the situation they are in they should be able to be assisted in this way, if they are competent and if they are suffering in such a way that they think it is time.

Senator KETTER: Do you think that safeguards could be built in that are going to protect those types of people?

Mr Boesen: We do not have the expertise to answer your question. I would assume that if one had a look at the 15 jurisdictions that brought in voluntary euthanasia surely they would have such safeguards built into their legislation. You presumably have an enormously large research team who could look at those safeguards.

Senator KETTER: Are you familiar with the Oregon situation?

Mr Boesen: No, I am not familiar with the Oregon situation. I have a few bits of information about it, but, no.

Senator KETTER: Are you aware that—and I think this is contained within one of the submissions that was presented to us—there was a study conducted in which there were 15 participants who received a prescription for a lethal drug who did not meet the criteria for depression, but three did. All three depressed participants died by legal ingestion within two months of this particular research being conducted.

Mr Boesen: I think that is a funny sort of submission. I have not read that specific submission, but pointing to the fact that a set of rules and regulations have not worked in the case of three people is scaremongering to some extent.

If you have a look other submissions, for example the South Australian Voluntary Euthanasia Society submission, they have put forward an analysis in attachment 1 to their submission—that is submission 3—which, taken as a whole, would suggest that where jurisdictions have introduced VE, or assisted suicide, that there has not been any detriment to outcomes. In fact, it is the other way around. I think rather than take one submission which purports that three people were inappropriately given access to a drug, that it needs to be taken in the context of the broader evidence that is available, which seems to suggest that the voluntary euthanasia and doctor-assisted suicide works and works well.

Senator KETTER: Are you familiar with the experience in Holland?

Mr Boesen: No I am not. What do you have there?

Senator KETTER: If you are not then there is not much point in asking about it, but—

Mr Boesen: Could I ask you whether you have had a look at the South Australian Voluntary Euthanasia Society submission?

Senator KETTER: No, but today it is my job to ask the questions, so with all due respect—

Mr Boesen: I am sorry. I was just trying to apprehend the context from which your question comes.

Senator KETTER: I was going to refer you to the writings of Theo Boer—who is a Professor of Ethics at the Protestant Theological University in the Netherlands—who was an advocate for euthanasia, but after the experience in Holland is now very much against it. I take it you are not familiar with that situation?

Mr Boesen: No I am not.

Senator KETTER: You are not familiar with the large increase in the number of people accessing voluntary euthanasia in Holland since its inception?

Mr Boesen: I do not think that is correct but, with all respect, that is not what our submission is directed at. We do not put forward the statistics for it; we have not briefed ourselves on that. Were we to brief ourselves—we both have research backgrounds—I am sure that we could find many people who would have a contrary view. I could not really respond logically to your statement in the absence of such evidence and information.

CHAIR: Senator Ketter, is there a particular submission that encapsulates that issue that you could refer to for these witnesses? If they would not mind—it is entirely up to them—they might like to have a look at that and perhaps in writing just—

Senator KETTER: I have not found it in the submissions. There may well be some submissions that deal with that, but I have been referring to information which is available on the internet. As I said, it is Professor Theo Boer and there are relatively recent articles out there reporting on his views about the particular issue.

CHAIR: I only raise that in case you might like to have a look at that and drop us a note saying whether you would agree or disagree. But I am not asking you to do that, I am just suggesting it to you.

Mr Boesen: I will certainly have a look at it. From my career as an educational research I can guarantee you that on any contentious issue I could find one person who would be very opposed to it and another person who would be very for it. To quote just one study is very risky.

CHAIR: We experience that all the time in our current jobs, I might say, so I understand what you are saying! Thanks very much, gentlemen. We very much appreciate your time and your effort in making a submission and being here today.

Mr Boesen: Thank you very much. We very much appreciate the opportunity to be here. We wish you all the best with the bill.

RYAN, Dr Christopher, Private capacity

[10:11]

Evidence was taken via teleconference—

CHAIR: Good afternoon, Dr Ryan. You have given us a written submission which we have numbered as lucky No. 13. This is, as you know, a public hearing. We are being broadcast. Your submission attracts parliamentary privilege. If you want to say anything in camera, you can make that request of us. If you want to in any way amend or add to your submission, you are able to do that now. But, otherwise, you can make an opening statement and then the committee will ask you some questions. First of all, it might be helpful for the committee for you to say who you are and what you are.

Dr Ryan: Thanks very much for the opportunity to speak to you. I am a psychiatrist. I am a special sort of psychiatrist, though. I am what is called a consultation liaison psychiatrist. That means I only see people who have a general medical illness in addition to their psychiatric illness. So if one of you were to have a heart attack—heaven forbid!—and go into hospital and the doctors who saw you thought you were depressed it is likely that it would be me, or someone like me, they would send around.

In addition to that, I have a longstanding academic interest in the intersection between medicine and the law in a whole bunch of different ways. That includes a relatively longstanding interest in physician assisted suicide and legislation around that, particularly the idea of getting that legislation right. It seems to me quite likely that that legislation will come, one way or another, so I am particularly interested in making sure it is the best legislation it can be. I am attached to the University of Sydney and an honorary associate with the University of Sydney's Centre for Values, Ethics and the Law in Medicine. That pretty much covers me. Do you have any questions on that aspect?

CHAIR: No. Thank you very much for identifying yourself and your specialty. Do you want to make a further opening statement?

Dr Ryan: Yes. I will just briefly go over the idea I put in the proposal. It is a relatively circumscribed idea particularly with regard to subclause 12(1)(3), which I will just remind the committee is:

... a further medical practitioner (the third medical practitioner) who is a qualified psychiatrist has examined the person and has confirmed that the person is not suffering from a treatable clinical depression in respect of the illness ...

That is one of the safeguards that is already in the proposed bill. I think, on the whole, that is a good safeguard, but I think it could be an even better safeguard through some relatively subtle but quite important changes in wording.

The thing I am particularly focusing on there is that there seems to be a suggestion in the way that it is phrased at the moment that you have to you get rid of clinical depression, that that is a bad thing. In fact, what we are really concerned about is whether the person suffers some sort of psychological or psychiatric problem that gets in the way of them making a valid choice, that gets in the way of their decision-making capacity or gets in the way of them understanding the information relevant to a decision—in this case, the decision to accept physician assisted suicide—or their ability to use and weigh that information.

On the one hand, that is broader than just, for example, treatable clinical depression. Another very common condition in the terminally ill is delirium or confusion related to the medical problem. Both of those things can cause problems with decision-making capacity. It is also in some ways narrower because it is not as if everybody who has treatable clinical depression will automatically be unable to understand information available to them or how to use and weigh that information to come to a decision. So I am suggesting it would be wise to alter that clause so that a psychiatrist is still involved mandatorily—I think that is a good idea, and I am happy to explain why I think that is a good idea—but the psychiatrist should be looking at whether the person's decision-making capacity is compromised. That should be the thing we are actually looking for.

There are some other minor changes I would make related to that. The bill goes on to use the term 'sound mind'. That is a rather archaic term for a modern legislation. You could use 'impaired decision-making capacity' or 'a loss of decision-making capacity'. By way of transparency, I should say, if it is not entirely clear from what I have said so far, that I am a supporter of the introduction of legislation to legalise physician assisted suicide—so much so, in fact, that I am on the New South Wales board of Dying With Dignity. I just wanted to be clear about where I am coming from.

CHAIR: Thank you very much for that, Dr Ryan.

Senator KETTER: Dr Ryan, I am interested in the paper you prepared that was attached to your submission entitled *Velcro on the slippery slope*. You mentioned in that paper that:

The temporary desire to end one's life is common in the general population [34]. Only very rarely though is this desire the result of a carefully considered, reasoned decision ...

You go on to talk about the fact that:

... the terminally ill population may also experience the desire for self-destruction ... however very little empirical work has been done on the aetiology of self-destructive thought ... Work that has been done supports the notion that suicidal ideation in this population is frequently not the product of a carefully considered and reasoned decision.

You go on to talk about the empirical evidence which supports that. It essentially is that:

... completed suicide is most common in the first year after diagnosis in the terminally ill.

It would appear that the people who are seeking access to voluntary euthanasia—or suicide, I suppose I should say—in these situations are people who are not giving considered thought to the idea. Could you address that?

Dr Ryan: I think it is the case that the vast majority of people who want to end their lives do so outside the sort of frame of mind that we would be considering if we were allowing people to die with physician assisted suicide. The classic person who you would allow to die by physician assisted suicide, if you had legislation, is someone who is terminally ill or, if not terminally ill, is certainly suffering a great deal, and has weighed up the advantages and disadvantages of going on, more or less, and has decided that it is really better to end it all. Probably in a lot of those circumstances, other people around them may well agree; their family or a bystander may agree—not everybody would, but many people might.

That is a pretty small group of people, which I suspect is reflected in the uptake of physician assisted dying in jurisdictions that have taken it on. Very few people actually take up this option. Most people who have a terminal illness do not want to die; they want to live as long as possible. People who try to commit suicide, on the whole, do not fit into that category. So all we are looking at here is a very small group of people who do fit into that category, and it is going to be important to design legislation to make sure that they are the only people that are accessing it. I think that is quite an important thing to do. I should also say that there are those people—they are real—and it seems to me cruel to forbid them from accessing this sort of help, assuming that we can protect everybody else.

Senator KETTER: You mentioned the Oregon situation, or I believe there is a paper attached to your submission which gives some information about the Oregon experience. The Oregon legislation appears also to seek to exclude access by people who are suffering depression to voluntary euthanasia. The paper talks about the fact that, despite those safeguards in the state of Oregon, there appear to be people slipping through the cracks.

Dr Ryan: Yes, that is exactly right. This goes to my contention that the mandatory psychiatric review, which is already part of the draft bill, should remain part of the draft bill. There are two ways to look at this argument. One is that if you add another person that the terminally ill person, who is in dire straits and wants to end their life, has to see then this is an extra burden for them, and it is likely to lead to at least some delays, particularly in rural areas. That is definitely a negative of having a mandatory psychiatric review; I think that is just the case. The positive side of that is that you are less likely to get the problems that probably exist in Oregon, where, even though people cannot access physician assisted dying in Oregon if they are depressed, there is no mandatory psychiatric review; it just depends on your physicians noticing that you are depressed, or delirious, and then referring you off to somebody who can check that out. That would be fine if we were confident that physicians were able to do that well. We know, and there is data that shows, that they are not; they often miss depression in the context of terminal illness, and they often miss delirium in the context of terminal illness.

The worry would be that without that additional mandated safeguard then you would get some people falling through the cracks. To be honest, it is probably not a huge number. Then it is just a question of people's preferences: are you prepared to let the odd person fall through the cracks to avoid everyone being further inconvenienced by yet another hoop that they have to jump through, or are you not?

Perhaps because of my profession, and also because I really do not like the idea of people being killed when they have not really made advance decisions that they want to be, my inclination is for adding the extra safeguard—despite the fact that I recognise that that is an impost.

Senator KETTER: Dr Ryan, are you familiar with the experience in the Netherlands with euthanasia?

Dr Ryan: Yes, I am relatively familiar with that. I have kept an eye on how that is going.

Senator KETTER: How do you think voluntary euthanasia is going? Do you think there are adequate safeguards in the Netherlands?

Dr Ryan: The Netherlands have a mandatory psychiatric review. They also have a bit of an odd set-up for historical reasons—the way it was brought in. I am not especially alarmed by the situation in the Netherlands, but

I do not think that set-up is the sort of set-up we would want in Australia. I think we would be much more looking towards the Oregon model—with, from my point of view, the addition of a psychiatric review on top of that.

Senator DI NATALE: I am interested in, firstly, the threshold question about whether psychiatrists should be involved. You mentioned in your submission that there is good evidence that non-psychiatrically trained doctors will miss major depression. What are you referring to there? What evidence?

Dr Ryan: There are a number of papers which I am happy to forward to you. I may even be able to find the references right now. The Gambini paper is a bit like this as well. They have asked physicians, 'Is this person depressed?' and physicians have suggested whether the patient is depressed or not. They have then brought a psychiatrist in later on to look at whether or not the person was depressed. It turns out that physicians sometimes thought people depressed who were not and frequently missed people who were depressed. The first of those is probably not so much of a problem, but the second certainly is.

Senator DI NATALE: When you use the word 'physician', you are including general practice as part of that?

Dr Ryan: Yes, general practice and specialist physicians. I think that the surveys have been mainly done with general practitioners and physicians. I do not think, from memory, there were any surgeons in the surveys, but one would imagine that surgeons would also not do very well. The reason for this is understandable. People diagnosed with depression are usually upset. They are usually not happy people. It would be odd if they were. So it is quite difficult to separate 'usual upsettedness' from a pathological process that you might call depression. It is the sort of thing that would probably be beyond a lot—not necessarily all; perhaps not even most—of general physicians or general practitioners. It is a tricky thing to do. The advantage that psychiatrists have is that six months of their training is devoted to psychiatric illness in the medically ill, so they should have a great deal of experience in making those calls. Physicians and general practitioners will not have had that training and will not have that experience.

Senator DI NATALE: Let us move into the issue of depression. This relates to the previous witnesses, who used the term 'rational decision making', which is very difficult to define. They made a similar argument—that somebody having clinical depression does not in and of itself mean that the person is unable to make a clear and, in their words, 'rational' decision. You use the term 'decision-making capacity'. What you are suggesting there is that depression in and of itself should not exclude you from being able to exercise your right under this legislation, but—

Dr Ryan: Not by necessity, although it would certainly make you cautious.

Senator DI NATALE: One would assume that in most cases people with depression do not have the capacity to make decisions in a way that we might define as rational, because the point is that depression does affect our capacity to make those decisions. But in some instances it may be appropriate; it might be a valid decision. One may have a terminal illness and be depressed, but you still feel that there will be examples where that person's decision making is not affected?

Dr Ryan: Yes. I am not sure that I would even go so far as to say that most people with clinical depression would lack decision-making capacity; it is just that a number would. This is a particularly important and irreversible decision, so you would want to be very clear about this.

I think I might have used 'rational' in that original paper from some time ago. I think it is better to look at the legal concept of whether the person has decision-making capacity and to work out whether the person's depression gets in the way of them understanding the information that is relevant to this. Frankly, it is not usually going to be that hard. For most people with depression, unless it is very severe, the understanding part is not going to be a problem. But it would be more common for it to get in the way of the second arm, and that is the ability to use and weigh that information to come to a decision. For example, you can imagine a moderately to severely depressed person who says, 'Thanks for telling me all that, Doctor. I understand all of that. But really I just know that there's no hope and nothing can be done. You say you can assist me with my pain, but I just know that's not going to happen.' In that sort of circumstance—I sketched a quick picture there, as opposed to a more detailed look—you can imagine that the psychiatrist may come back and say, 'No, I think the person's depression is getting in their way of being able to use and weigh the information. They just see everything as bleaker than it actually is, and they see it that way because of the depression.'

Senator DI NATALE: And that is obviously something that requires a specialist assessment?

Dr Ryan: It does require a specialist's assessment. Some physicians and general practitioners can do it, and they can do it well, but they will not be able to do it with the same amount of reliability as a psychiatrist.

Senator DI NATALE: Yes, that makes sense. Your specific suggestions around the redrafting of subclause 12(1)(e) make sense in that context. Let me ask you about one of the other things that has come up quite regularly, and that is the issue of terminal illness.

Dr Ryan: Sure.

Senator DI NATALE: Again, a previous witness has said, 'We need to expand it. It should not just apply to somebody with a terminal illness.' What is your view?

Dr Ryan: I think it probably is unfair to just apply it to somebody with a terminal illness. There have been cases in the UK recently where people who did not have a terminal illness but who had had strokes that led them to a situation where they found their lives unbearable and where they could not end their own lives—except by starving themselves—were not able to access legislation that was just for people with a terminal illness. They were in a situation where they had to, in this case, starve themselves. This is a very small number of people—a tiny number of people. I would have thought, in the best of all possible worlds, you would design legislation that would also take account of that tiny number of people. I recognise, though, the wider you make the legislation, the more people will, understandably, worry that perhaps some people will access the legislation who are not the sort of people we want to access the legislation.

Senator DI NATALE: That is my point. That is the tension we are balancing at the moment. As legislators, we have to make a decision on that. Do you have a view about which way we should move? Are you suggesting that we should cater for that small number of people, recognising that perhaps people who are not the intention of this legislation also have the opportunity to access it?

Dr Ryan: I would think it should be possible for legislation to include those small numbers of people but not create a list of more people being involved. I recognise that there is a tension there. In my opinion, it is possible to do; but I have sympathy for people who say: 'No, hang on. That's bad luck for those two or three people. They're just going to have to suffer.' That is fine, although it does mean actual suffering for those few people.

Senator DI NATALE: Yes. Let me just finish with the *BMJ* article that you referenced on the prevalence of depression and anxiety in patients requesting a physician's aid in dying. That is the Oregon experience. The conclusion there was that, while a number of the people who were reviewed did not meet the criteria for depression, there were three who met the criteria for depression but who died by lethal injection.

Dr Ryan: Yes.

Senator DI NATALE: Taking your point that depression in and of itself should not preclude people from making this decision, do we know whether the three depressed participants who had decision-making capacity were able to make that decision?

Dr Ryan: No, we don't

Senator DI NATALE: In that case, it may in fact be that had they received a psychiatric assessment they may have been diagnosed as depressed; but, in fact, the assessment was that they had decision-making capacity and were able to exercise their right under law.

Dr Ryan: It is distinctly possible. With only three people, it could easily have been that all people were competent; it could easily have been that none of the people were competent. All the study does is just raise a concern.

Senator DI NATALE: But, again, it is not an argument to say, 'Well, there are unsurmountable flaws.'

Dr Ryan: No, not at all. I would have thought this particular flaw could be surmounted in exactly the same way I have been talking about it.

Senator DI NATALE: Good. I think I am done. Thank you, Dr Ryan. There is a lot of debate about the role of the psychiatrist in this legislation, and it may be helpful if you could point to any evidence which demonstrates that depression and delirium in people with medical illnesses is missed by physicians. I think that might help us in further deliberations.

Dr Ryan: That is no problem at all. I know in the 1990 article that there are four references to it; but I can also pull out some more recent references.

CHAIR: Dr Ryan, I am just finalising these questions. I note in your paper titled *Velcro on the slippery slope* that you say in relation to the Netherlands issue: 'Moreover AVE has been practised without prosecution in the Netherlands for over a decade and there is no evidence of any moral decay in Dutch society.' You reference a 1994 paper by Mr P Singer—whether it is Mr, Mrs, Mr or Dr, I am not sure.

Dr Ryan: I think it is 'professor'.

CHAIR: Does it mean to say that you do not accept the concerns that have been raised about the Netherlands experience?

Dr Ryan: As I said, I am not a particular fan of the way that the Netherlands have constructed their access to the euthanasia regime. It has not been constructed in the way that we construct things. It is very much a European and particularly a Dutch way of doing it. I am sure the committee would know that, originally, it was not legislation; it was that you could kill your patient, but you would not be prosecuted if you did certain things. Those things were codified and then that was turned into legislation. I do not think the Netherlands is now a cesspool of people being killed willy-nilly, but I also do not think it has set things up as safely as it could have done. Oregon is a much better model. And I think an improved Oregon is an even better model.

CHAIR: Thank you very much Dr Ryan. I appreciate your time is very valuable, so the committee is very grateful for your contribution by way of your submission and your evidence today. Thank you very much for that.

Dr Ryan: Thank you very much.

WALLACE, Mr Craig, Convenor, Lives Worth Living

[10:40]

CHAIR: I now call our next witness, Mr Craig Wallace, the Convenor of Lives Worth Living. Mr Wallace, thank you very much for joining us. I do not think you were here earlier, so I will just briefly mention that these are public hearings; we are being broadcast. It is a parliamentary hearing, so parliamentary privilege applies. If you wanted to say anything in private you should indicate that to us.

Your submission has been received. It has been numbered by us as No.165. If you wanted to make any amendment or addition to your written submission you could do so now, otherwise could you give us a brief opening statement and then the committee will ask some questions.

Mr Wallace: Lives Worth Living is a disability advocacy group working around issues on eugenics and euthanasia. Firstly, thank you for the opportunity to make a submission, to give evidence here today and also to submit a late submission. As you are probably aware, there are a number of things dividing our attention in the disability rights community at the moment, including the National Disability Insurance Scheme and some budget changes. We appreciate the opportunity to make a very brief submission.

If it is helpful, I might provide a bit of detail to expand on what was a brief submission and explain where we are coming from. Lives Worth Living is a network of Australians with disability speaking out about euthanasia and eugenics. We are not a mass membership organisation; we would probably describe ourselves as something akin to a ginger group or a group of thought leaders in the space. We have a core group, which is Joan Hume, John Moxon, Daniel Pask and me. What we have in common is that we are all either leaders of organisations in the disability community with a mass membership, or past leaders of organisations. We also have a social media footprint of about 300 people who engage with us in that way.

A point of difference from other groups advocating in this space is that we do not come from a religious, ideological or pro-life position. I certainly do not. We come at this from a human rights and disability rights perspective. I also happen to be the elected president of the national peak body, People with Disability Australia, which has a footprint of about 17,000 members and followers around Australia.

While it is true that there is not a united, or unified, position on euthanasia, I can certainly say that the centre of gravity is shifting on this one. While I am not representing PWDA in this hearing, that organisation also has concerns that we have now adopted this policy and very grave doubts about the introduction of voluntary euthanasia without a level playing field of supports and guarantees for people with disabilities.

Turning to the bill, if that is useful: I want to start off by saying that I have a lot of sympathy with the idea that our bodies are our estate and that if you had something like terminal bowel cancer that was inoperable that you might want to die. I have had family members who have been in that situation, as, I suspect, have most Australians and most of you. In many ways, I think that kind of condition is the diagnostic face of euthanasia.

In a world with total empathy, where we all understood what we meant all of the time, I might support voluntary suicide. But we do not live in that world of crystal clarity, so my concerns are about the definitions within the bill of words like 'voluntary', 'terminal and 'unacceptable', and how these will be interpreted by mortals. Many of us with disability in the community will happily regale you with stories that point out that doctors are very mortal. There is nothing like being told that you will never work or that you should have been dead years ago to focus your mind on the mortality and the subjectivity of the medical profession.

There is not some kind of clear dividing line between disability, illness and a medical condition that means you can clearly quarantine a bill like this to one set of people, unless you were to actually name the illnesses involved. I have been through a couple of these bills now that have come out of state parliaments, usually as private members' bills, and none of them went to that level of granular detail.

The bill defines, as you know, 'terminal illness' as one which, in reasonable medical judgement, will in the normal course, without the application of extraordinary measures or of a treatment unacceptable to a person, result in the death of that person. It also mandates that a person needs to experience pain, suffering, distress or indignity to an extent unacceptable to that person. I have to say that I am not satisfied that this would not apply to the people who I represent on a reasonable reading. For instance, I have known many people who have incurred—and we got people within Lives Worth Living—high-level full spinal injuries that have left them as quadriplegics. I am concerned about how those people might be impacted by this bill. I have some questions that point to that.

When does an illness actually become terminal? Most medical practitioners would say that an illness like a high-level spinal injury shortens the lifespan. The certificate in the schedule at the end for medical practitioners says that the illness has to ultimately result in the death of a person. There are people who want to expand

euthanasia beyond terminal illnesses, as we just heard in the last sitting. I would ask what are 'extraordinary measures'? It is interesting wording. I often hear about heroic measures being used in medicine. Is having a catheter, a bowel diversion, a stoma or a ventilator to help you breathe something that would constitute an extraordinary measure? Any one of a number of interventions might conceivably fit this.

When does pain, suffering or indignity become unacceptable to a person? To paint a picture for you of their lives, a person with that kind of disability, might be unable to walk, unable to move their hands, unable to eat without assistance, unable to shower or unable to evacuate their bladder or bowels without the support of another person. There is pain, suffering and distress in all of this. I know people with disabilities who look like this. I have visited them in rehabilitation wards. At the time they acquired the disability if you asked them they would have said: 'I want to die. I want them to switch the ventilator off right now.' Yet I have talked to those same people two or three years down the track and they have gone on to live lives that involve productive careers, that involve starting families and that involve taking leadership positions in my community. If you asked them that question again they would say: 'No, I do not want to die now.'

The degree to which a disability is acceptable depends on the level of disability supports, technology, adaptive aids, formal and informal help around that person at the time. It also depends on time. It changes back and forth. We get depressed like everybody else. There are good times and bad times. Sometimes it changes due to issues that have nothing to do with people with disability. We work in PWD with a large number of people who are non-verbal, which means they cannot communicate easily, and they will complain that their lives have become intolerable. When we go into that deeper it is actually because they cannot get access to an accessible dentist and they have been dealing with a range of other medical issues in their lives that have nothing to do with the underlying condition. We also work with people who are subject to abuse, mainly from people close to them and sometimes as a result of the wrong kind of care, including from within the medical profession.

I support, as you would know, the National Disability Insurance Scheme and the difference that that will make in the lives of people with disabilities like that. The reality is that we do not have the full NDIS now. It is rolling out in stages and in small trial sites around the country. We believe the proper support, not suicide, is the decent path to better lives for those people. I am not sure that everything is being done for those people medically who experience conditions like nausea and extreme pain—for instance, medical cannabis. The use of that actually being introduced is something 12 months ago I probably would have said, 'Don't contemplate it.' Now I would be thinking about it.

The bill creates an offence around influencing a doctor to provide dying with dignity services, and that is a good thing. But the coercion that I am worried about is different. It is not doctors; it is the coercion of people with disability to take our own lives—people who might already be in abusive relationships, who might be seen as a financial or logistical burden on their families, who might be threatened with loss of their disability supports. This coercion does not need to be a kind of sinister cast; it can be as simple as a young man with a disability being faced with the choice of the family saying they are going to withdraw supports and you will end up in a highly medicalised nursing home, reading five-year-old copies of new idea and surrounded by dementia patients that you are afraid of. I am not talking hypotheticals here; I am talking about people that I actually know here in Canberra who have been in that situation in nursing homes in the region.

I oppose introducing euthanasia in a toxic climate. Many of the public debates around disability position us as better off dead—as people who are wasters, who are leaners and who make no contribution to our society. You do not have to look very hard to find people advocating involuntary sterilisation of people with disability and the removal of people with disability on the basis that we add no value. You do not have to look hard to find stories on the front page of our major newspapers that talk about people on disability pensions as rorters.

The last thing I want to talk about is suicide prevention and the notion of euthanasia as suicide. There is a double standard in the way we treat suicide and disability. We can call this 'dying with dignity', we can call this 'euthanasia', but the reality is that euthanasia is suicide in the same way that calling 'enhanced interrogation' is a blind for torture. With any other group in the community who are contemplating suicide because of external circumstances in their lives, we would see our project as a community as stopping them from doing that. If it were women are trapped in a cycle of domestic violence, we would be directing them to Lifeline or to counselling services. For young gay and lesbian and transgender people, we have a project that is called It Gets Better that is aimed at convincing those people that there are lies for them beyond bullying, harassment and isolation. I ask: where is It Gets Better for people with disabilities—to say that to those people that you can live good lives beyond disability? Arguments about slippery slopes often have the odour of intellectual bankruptcy. Yet, with this issue, there actually does seem to be a slope. In every jurisdiction where it has been introduced euthanasia has spread to a much wider group of people than was intended. My mind was crystallised on this issue by the case in

Belgium of the two twins who were deaf and had Usher syndrome and who were perfectly healthy but feared going blind and were granted euthanasia.

Lastly, the bill does not provide protections under the UN Convention on the Rights of Persons with Disabilities, which has been ratified by Australia. Article 10 of the convention, which people with disabilities strongly lobbied for, provides:

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

In my notes I have actually got that last bit italicised, because it is actually about the equality of outcome that is important. Euthanasia is not acceptable to the disability community until we have the same supports, rights and opportunities for a good life which are available to other Australians, and to make our lives worth living and worthwhile.

CHAIR: Thank you very much, Mr Wallace. That was a long opening statement. I let you go, because it clearly addressed a lot of the questions we would have asked. I acknowledge that this is a big 'if' but if all those supports that you mentioned were there, would you have a different view?

Mr Wallace: If we lived in a different kind of world and a different kind of community, and we had very clear understandings of what people wanted free of external pressures and free of the lack of supports, then I think we would be talking about a different situation here. I would still see our project for people with disabilities, though, as diverting them from suicide, not encouraging them to take it, because we do not do that for any other group in the community.

CHAIR: We live in this society and that is unlikely to change, but if all of those supports that could be physically bought with money, some of which you have mentioned, were there would you have a different view, recognising that we live in Australia and Australia is what Australia is?

Mr Wallace: I think it would soften our attitude towards it. At the moment, we see so many people that are almost already afraid of involuntary euthanasia. They are afraid that they will go into hospital and be denied hydration and food because people who are looking after them see their lives as intolerable outside of a medical environment because of the lack of supports.

Senator DI NATALE: It is important to get a disability perspective on this. You finished by saying the disability community do not accept this, but you are not speaking on behalf of the entire disability community, are you? There are people within the disability community that I have spoken to who would support that. So do you accept that there are different views and not a consensus?

Mr Wallace: Absolutely. People like Kelly Vincent, for instance, would be worth talking to. She has a different attitude to this. I am saying that the centre of gravity on it has shifted—that is my perception of it. I am the elected head of that peak body. They do not have the same position as Lives Worth Living but we now take the position that we are very concerned about euthanasia, that we oppose it for children under any circumstances and that we believe that the supports are not there to mandate its introduction at this point of time.

Senator DI NATALE: You mentioned quadriplegia, but it would not under any definition classify as a terminal illness.

Mr Wallace: Why?

Senator DI NATALE: There is no medical definition that would include quadriplegia as a terminal illness.

Mr Wallace: Your lifespan is shortened.

Senator DI NATALE: Living is a terminal illness, if we are going to apply that definition.

Mr Wallace: That is right, but with quadriplegia your lifespan is considerably shortened.

Senator DI NATALE: Given that this is a process that involves an assessment, as the bill is currently drafted, by two doctors and a psychiatrist, there is not any medical body that I am aware of that would view something like quadriplegia as a terminal illness. I do not know how it could be interpreted in that way.

Mr Wallace: I have spoken to people in rehab units who have been told by doctors that they will get five years out of this—and these are people that are being seen by multiple doctors and locums.

Senator DI NATALE: The official position in the medical community would not recognise something like quadriplegia as a medical illness, and that certainly would be the intent of the legislation. You said that one way it may be worth addressing it is to identify specific conditions. The counter-argument is that you would get an exhaustive list and would probably leave things out and so on. What about turning that issue around, perhaps, and including an exclusion around specific disabilities to make it clear that that is not the intention of the legislation?

Mr Wallace: The problem is that there is not that fine line between a disability, a medical condition and an illness. There is not a clear demarcation that I can see. The other problem is that, if we create the idea that euthanasia is a right to be exercised, it will be inevitably demanded by other groups of people. You say, Senator, that there is a definition of terminal illness. I have not seen that definition—

Senator DI NATALE: I am saying there is a widely accepted understanding of what a terminal illness is within the medical community, and I do not think that, under that understanding, anybody of any standing within the medical community would accept that something like quadriplegia is a terminal illness.

Mr Wallace: We just heard Dr Ryan saying that there was a case for this to be extended beyond what he regarded as a terminal illness. I am not clear that there is that consistent understanding of what a terminal illness is, aside from the fact that it is eventually going to mean that you die or that you have a shortened life span, as is stated in the certificate. If there is such a definition, if it could be created, if there could be crystal clarity that it did not mean the kinds of people that I was talking about, I would be a lot more comfortable.

Senator DI NATALE: Well, that is helpful. One of the ways of perhaps looking at the impact of this is that, in those jurisdictions where it is in existence, for example, in Oregon, there is no evidence at all that there are concerns that the disability community have faced undue pressure—I am trying to use the language that you use—subtle, emotional, financial and personal pressures. So there is nothing that I am aware of where that has occurred, and I think it is often worth just looking at. It is happening already in Oregon. Is there anything in the Oregon experience that gives you cause for concern?

Mr Wallace: My understanding of the Oregon experience is that it is relatively fresh, that the nations that have had euthanasia for some time are the low countries. So we have mainly looked at Belgium, the Netherlands and countries like that, where there has been a clear creep into other areas of disability, and even beyond what some people might regard as disability. For instance, people with depression or even anorexia are stepping up and saying that their lives have become unbearable, and we are worried about that inevitable creep and we would be interested to see the outcomes of the Oregon experience.

Senator KETTER: I was just going to clarify, for the benefit of the witness, that the Oregon example has a specific requirement that the patient has a terminal illness that would, within reasonable medical judgement, cause death within six months. I think that is a different situation to what is being proposed under this bill.

Senator DI NATALE: Again, it is a draft bill. I think that is very useful. If that sort of language were incorporated into this bill, would that make you more comfortable?

Mr Wallace: To some extent I am concerned about those kinds of time frames because I simply believe that medical opinions on those matters, following a catastrophic injury, can be flawed, that they are subjective. I have met people who have been, 'You've just had a catastrophic injury,' and I have had people who have been told that they will never wake up from comas and then have gone on to live with an acquired brain injury. I have had people with high-level spinal injuries who have been told that they have got a life span of five years—there may be others who have been told they have got six months. It is the subjectivity of those opinions that concerns me. Having said all of that, I do not want to be disingenuous. I would certainly be happier with something that was very much contained, because I think the experience that we have all had, and that the people who advocate for euthanasia are now struggling with following the Nitschke experience, is how they actually confine this to the very few so that it becomes an option of last resort. I think that is what we are all struggling with. The reality that I struggle with is that the demarcations and lines across disability and terminal illness are not at all clear to me.

Senator KETTER: I think you have touched on this area in particular, but in your submission you have said you are concerned about legalised suicide for people with disabilities having the potential for abuse and perverse outcomes. Are there any further examples you want to provide to us in relation to that?

Mr Wallace: Yes. I am concerned about people being leveraged into suicide as a result of a raft of subtle pressures going on in their lives. Voluntarism within families is a movable concept at the best of times, let alone when a family is facing an illness, facing financial stresses coming from that, facing the logistical stresses of looking after someone. So I am very concerned about people being levered into suicide. I am very concerned about the kinds of perverse outcomes that we have seen in Belgium, with the two deaf twins who had disabilities being levered into suicide. I am very concerned about depression being underdiagnosed in our community and about the fact that there is no project to address suicide itself amongst people with disabilities. If this were a woman trapped in a cycle of domestic violence that was spiralling out of control, we would do everything in our power to ensure that that person was connected to services that ensured that that person had a way out of that situation. It can be the same with people with disabilities. Many of the things that trap us and make our lives intolerable are also solvable.

Senator KETTER: You have mentioned that you have been examining the experience in the Low Countries. The Netherlands experience is also something which attracts a fair bit of media attention. Have you had an opportunity to look at that country's experience with voluntary euthanasia?

Mr Wallace: We have had some. We are concerned about the creep beyond a group of people that most of you would imagine as being people with terminal illness, which are the clients of that euthanasia legislation. We are concerned about reports of mobile clinics visiting people and providing them with assistance and advice. We are concerned about there seeming to be a fall away in some of the disability supports that people experience within that. That almost becomes the default utilitarian option for people with disabilities. Disability rights, believe it or not, actually does not have a large footprint in those countries over time, and I do not think that is the way Australia or our project for disability want to go as we move into the National Disability Insurance Scheme.

Senator KETTER: Thank you.

CHAIR: In relation to the Dutch experience, which I am not really familiar with—I have read about it occasionally in the papers—Dr Ryan seemed to suggest that it was quite a different sort of legal regime that had grown up out of practice that was happening rather than starting from the beginning. The exposure draft is, I assume, quite different from that. Do you have any understanding of that?

Mr Wallace: One of the arguments for this is actually that you are regulating something that is being practised anyway and being practised poorly, and I do acknowledge that that is an argument for this.

CHAIR: You are saying voluntary euthanasia is being practised in Australia now?

Mr Wallace: No, I am saying one of the arguments based on the Netherlands experience as I understand it. I have not been there and am reluctant to comment on places I have not been to and jurisdictions I have not experienced, but nonetheless my understanding of the literature on this is that voluntary euthanasia was being practised widely by the medical profession in the Netherlands before it was regulated and that the legislation was brought in to regulate a situation that was already almost slipping out of control of the legislators. I am not convinced that it is the same here in terms of people with disabilities. When we experience people with disabilities who are non-verbal and going into hospital and they are attempting to deny them food and hydration, the disability rights movement goes in and advocates for those people. That is a difference between here and what I understand is happening in the Netherlands. My concern about legislating this here without very clear understandings of what a disability is, what a terminal illness is, what voluntary is and what coercion is is that we will potentially wind up creating more instances of this via legislating on it.

CHAIR: Okay. Thank you very much for your help, for your submission, for your opening statement and for the time you have given us today. We very much appreciate it.

Proceedings suspended from 11:11 to 11:22

BEST, Dr Megan, Office of the Archbishop, Anglican Church, Diocese of Sydney

CHAIR: I welcome Dr Megan Best. Thank you very much for being with us. I do not think you were here earlier, so I will just remind everybody that this is a parliamentary inquiry and that parliamentary privilege applies. If, for any reason, any of your evidence needed to be kept confidential, you should raise with that with the committee. You have made a submission, submission No. 27. Do you want to amend or add to that written submission?

Dr Best: No.

CHAIR: Would you like to make an opening statement?

Dr Best: I am here as a representative of Archbishop Glenn Davies of the Diocese of Sydney. I am a member of the Social Issues Committee of the Anglican diocese, which advises the archbishop. I am also a palliative care doctor who works in Sydney. I have some comments which the archbishop has asked me to make on his behalf.

Thank you for the opportunity to make my remarks to the committee today. I regret being unable to address you in person, but one week's notice was insufficient to permit my attending. Nonetheless, I am grateful for Dr Megan Best who is representing me on this occasion.

As I have noted in our submission, the issue before us is of grave importance for our nation. I am opposed to the bill under consideration and am concerned about its failure to understand and protect the rights of terminally ill people. I have four reasons for my view. Firstly, I am not persuaded that a right to request euthanasia or physician-assisted suicide exists, and I find the way it is recognised in this bill to be extremely problematic. The assumption of such a right in this bill obscures the fact that its existence has not been established. Such a right is not recognised in Australian law, or in international charters of basic human rights such as the United Nations. Furthermore, use of language such as 'dying with dignity' in place of euthanasia and physician assisted-suicide frames the issue in an emotive manner which obscures distinctions of enormous moral importance, most significantly between suicide and death at the hands of another. Moral questions are obscured when they are discussed in such emotionally loaded terms. The issues at stake are far too important for this. Framing the practices of euthanasia and physician-assisted suicide as medical practices avoids recognising the fact that the notion of a doctor killing their patient is diametrically opposed to the traditional role of the doctor as a preserver of life, as expressed in the Hippocratic oath. Too many important issues are being avoided by the framing of the notions under examination in the current review.

Secondly, evidence from other jurisdictions clearly demonstrates that euthanasia and physician-assisted suicide cannot be controlled by legislative safeguards. In our submission, we expanded on evidence from a number of countries where similar laws are in place, which shows how easily such safeguards have been avoided and ignored. These laws have been used by citizens who were never intended to be eligible for euthanasia, such as people who are neither physically ill nor mentally incompetent. Given the gravity of the issues at stake and the potential for misuse, we believe that this bill should be abandoned. My representative can discuss this at greater length if required.

Thirdly, the bill fails to adequately recognise the reality of modern palliative care practice. While we recognise that there are cases where suffering persists despite the introduction of palliative care, this bill does not take into account that palliative care can change a patient's attitude to hastened death, but that this occurs only after care has commenced. A requirement to simply discuss palliative care, as found in this bill, is totally inadequate. If we truly want to help terminally-ill patients we should make sure that they have the opportunity to access palliative care. In contrast to a putative right to assisted death, the right to palliative care has been recognised internationally.

Finally, I have grave concerns about aspects of the bill. The definitions in this legislation are unclear. For example, there is no definition of terminal illness in terms of prognosis. Some cancers, known to be terminal, may have prognoses of over a decade. Neither are the terms 'distress' and 'indignity' specific. I note, from other submissions, that a wide range of diseases, apart from terminal illness, have been recommended for inclusion—even to the point where a subjective complaint of suffering from any cause should suffice as reason to access the services of this bill. This lack of clarity runs the risk of this legislation being used by a much broader segment of the population than just those whose death is imminent. Similarly, the lack of precision in guidelines for the doctors involved to determine whether the patient is of sound mind or making a voluntary decision raises the possibility of the legislation being used in ways other than intended. I have highlighted other concerns in our submission.

The impact of death is never limited to the one who dies. Those around them must be affected, because human beings exist in relationship. I do not believe that either euthanasia or physician assisted-suicide is ever a legitimate

course of action for a patient or a doctor. Even if it were to be justified morally, I do not believe it can be legislated safely. I fear for the safety of some of the most vulnerable people in our society if such laws were introduced: the elderly, who are subtly coerced through being made to feel a burden on their carers; the suicidal, for whom we legitimise death as a valid solution to psychological distress; the average citizen, who is scared of dying because we do not discuss it in our society and want to avoid it at all costs; and the ill and disabled, whose lives are devalued as assisted dying becomes a therapeutic option at the end of life for all Australians. I urge the committee to vote against this bill, in the name of justice and in the name of love for the vulnerable in our community.

CHAIR: Dr Best, did you want to add to that, with your experience as a palliative care doctor?

Dr Best: I have had patients request euthanasia. In my experience it is a cry for help, and on further discussion of the request with patients I have found there are issues that promote the cry for distress that are not meant as a request for me to kill them. It is a request for more support. Furthermore, I am in the final stages of a PhD, looking at suffering and spiritual needs at the end of life. My research is demonstrating that the suffering at the end of life is not currently recognised fully for what it is, and that there are therapeutic options available for managing suffering at the end of life that can relieve the suffering of the patient involved. Therefore, I see that suffering at the end of life is not a reason for assisted dying. I think it is a reason for more intense therapeutic support of the patient.

Senator KETTER: Could I clarify what your qualifications are?

Dr Best: I am a medical doctor, with special qualifications in palliative care.

Senator KETTER: In Dr Davies's submission there is a comment there about the fact that advances in palliative care have not been adequately factored into the euthanasia debate. Are you able to talk about some of those advances?

Dr Best: I think it is important to note that palliative care is a fairly recent development in terms of medicine. When I went to medical school there was no mention of it. I was not taught how to treat pain. Enormous advances have been made in the last 10 or 20 years in terms of what we are able to offer patients, in terms of relieving symptoms generally, and in terms of the psycho-social supports we are able to offer. However, because it is a fairly recent development there are still many doctors in the community who are not aware of what is available. We are still not being referred all the patients who would benefit from palliative care. I am sure that Palliative Care Australia would have put in a submission indicating that there are still areas of Australia where adequate palliative care access is a problem. So the full advantage of developments in palliative care over the last decade or so is not being experienced by many Australians.

Furthermore, we know from jurisdictions such as Oregon that when palliative care was instituted around half of patients changed their mind about whether they wanted assisted death. So it is not fully understood that you need to experience palliative care before you can make an informed judgment on whether it will be acceptable to you.

Senator KETTER: It was a greater percentage—2.8 per cent presented for treatment and requested euthanasia, but then fewer than one per cent—

Dr Best: In Australia, where it is not legalised, more than half of the patients who request euthanasia cease in their request once that care has been instituted. I think if somebody is in severe pain and they are greatly distressed it is very difficult for them to make an adequately informed choice, because they often cannot imagine what it would be like to be out of pain. The experience of what we call total pain or existential suffering at the end of life is an all-encompassing experience that makes it very difficult for people to imagine being in any other condition.

Senator KETTER: It is extraordinary to me that doctors are not aware of the full advances of palliative care.

Dr Best: I work in community palliative care, so I work at the interface with the general practice population. I find general practitioners are very willing to learn, but certainly a lot of them do not understand how even basic pain medications are used in many cases.

Senator KETTER: There is reference in Dr Davies's submission to the Dutch experience. There is reference to the fact that there are Dutch doctors who said if they had known more about palliative care they may not have assisted with euthanasia.

Dr Best: That is true. I was in Holland last year and had a very long conversation with one of the members of the oversight committee in the Rotterdam district. I also spoke to a patient who had been treated by an oncologist, and when the curative treatment was no longer working the oncologist recommended to the patient that it was time to consider euthanasia and there was no consideration of referral to palliative care. In my discussion with the

Dutch doctors at that conference I found that they certainly did not have the access to palliative care or the understanding of palliative care that we have in Australia.

CHAIR: What is the oversight committee?

Dr Best: One of the conditions of the Dutch legislation is that the doctor will not be prosecuted for assisting a patient in their dying so long as they report what they have done to a committee, and there are five committees through Holland. The very first case of someone actually being prosecuted for assisting a patient in dying has just been reported, and that was for a doctor who assisted in the death of a patient who did not want to go to a nursing home.

CHAIR: What are the status, standing and powers of the oversight committee?

Dr Best: The oversight committee can recommend that a particular doctor be referred to the prosecutor to be charged for the death of a patient, if it is not done under the guidelines in the Dutch legislation.

CHAIR: Does that committee—

Dr Best: It is a review committee. They review the paperwork the doctors send in, having assisted a patient to die. However, it is understood that not all cases are reported to the committee.

CHAIR: What sort of people comprise the committee? Are they qualified in any way—policemen or doctors?

Dr Best: The ones I have spoken to are ethicists. I am also an ethicist. I am trained in bioethics.

Senator KETTER: Dr Davies's submission talks about concerns in respect of the definition of terminal illness in the exposure draft of the bill. Could you elaborate on that please?

Dr Best: In the jurisdictions where euthanasia has been legalised we are very concerned that once it is considered that there are some lives not worth living, which is the case when a doctor decides to go ahead and agree to a patient's request for assisted dying, it is human nature to think that what is available to one group of the population should be available to other groups of the population who requests similar services. So if you do not have tight definitions it is easy for someone who wants to help a patient who is suffering to justify inclusion of illnesses that may not traditionally have been considered terminal illnesses. I know that you have had some discussions on this topic with people giving testimony today.

We are concerned about this with illnesses that reduce the lifespan. A gentleman previously referred to quadriplegia. You could say that diabetes is a life-limiting illness. Many people with diabetes will die of their disease. However, they may not die of their disease for a long time. But even cancer, which I think many medical practitioners would say may be a terminal illness once it reaches its metastatic stage, can still allow a decade of life before the actual terminal event occurs. So we think to just refer to terminal illness opens up the legislation to a wide group of people.

It is not that we think that if we are able to pin down the definition of terminal illness the problems would be overcome. In the jurisdictions where the laws have been brought in and have initially been recommended for people with a short prognosis and who are mentally competent they have been expanded to include those who are not physically ill and who are not mentally competent.

CHAIR: That would not be possible under this draft bill, though, would it?

Dr Best: It could be approved by the courts, which was the case in Holland.

Senator DI NATALE: Not under this bill.

Dr Best: There was legislation put through in Holland that said that patients who were able to access the legislation had to be mentally competent, but we know from the Dutch government report that hundreds of patients who are known to be mentally incompetent are killed each year.

Senator DI NATALE: That is totally different legislation, though. That is a completely different legislative framework. I am not sure how you can translate the experience in Holland to what is being proposed here. I am not sure what the relevancy is, actually.

Dr Best: Okay, then let's talk about the Oregon experience and the number of patients who are lost and not followed up on and we have no idea what happens to them. The fact is that the reports sent in rely entirely on the doctor involved—

Senator DI NATALE: You mentioned the Dutch model. You were highlighting that it would be contestable in the courts—

Dr Best: That what is available to one sector of the community should be available—

Senator DI NATALE: No, whether somebody is mentally competent and has the capacity to make a decision or not.

Dr Best: No, I am not saying that someone who is mentally incompetent has been given the right to make a decision. What is happening is that the doctor is making the decision for them.

Senator DI NATALE: The discussion previously centred around whether, under this legislation, a person should be deemed, to use the words of some of the previous submitters, to have the capacity to make the decision. You implied that in Holland those decisions were made by the courts.

Dr Best: No—the decision to make it legal for people to have euthanasia if the courts do not prosecute the doctors for assisting in the death of mentally incompetent patients.

Senator DI NATALE: That is a separate issue.

Senator KETTER: I note that there were some concerns about doctors having relationships in relation to euthanasia in the process envisaged by the bill where two or three doctors have to be satisfied that the patient meets the criteria. There have been concerns expressed about relationships between doctors being formed to circumvent some of the safeguards in the bill.

Dr Best: Yes. Under the current legislation, you have the first doctor who receives the request from the patient, a second doctor who has to affirm the diagnosis, the third doctor involved is a psychiatrist and the fourth doctor involved is a palliative care specialist. We certainly think that this is by no means overdone in terms of making sure a patient is actually eligible for use of this legislation. However, there are several issues involved. One is that in Australia there are a lot of patients in rural and remote areas where it may be difficult to access these doctors. We are concerned that it may be difficult for people to access some of these doctors. The understanding is that the first doctor is in a position to really understand what is going on with the patient, but if the doctor is someone who is not well known to the patient then perhaps they may not understand all the issues. Please forgive me, Senator Di Natale, but what has happened in Holland is that they had a lot of difficulty finding doctors who were happy to cooperate with the legislation. So doctors now travel in minivans to a patient to provide the dying with dignity services—in which case, they certainly would not know the patient.

Secondly, to get the second, third and fourth doctors' signatures for this legislation would certainly involve doctors who did not know the patient certainly in cases of remote Australia but even in suburban areas. So to have one meeting to ascertain such a complex issue as whether or not there any psychiatric issues which may impair the capacity of this patient may not be sufficient. One appointment may not be sufficient to address such a complex issue. Also, if it is physically required for two doctors to be present to sign a piece of paper then, in the name of efficiency, some doctors may call on a friend to do it remotely and they may not actually see and examine that patient. This is happening in other jurisdictions just because doctors are busy people and want to save time. They may not be doing it for any deliberately malevolent purpose but rather just thinking they were helping the patient. I am not saying there is a malicious intent. All I am saying is that this is certainly possible and would reduce the level of oversight that is intended through this bill.

Senator KETTER: My information is in respect to Holland. I wonder whether you could confirm if on average those physicians see a patient three times before administering drugs to end their life. Is that your understanding?

Dr Best: Some doctors only see a patient three times. Professor Theo Boer, who is an ethicist at Utrecht University, was one of the architects of the Dutch legislation. He has recently written to the UK parliament in light of Lord Falconer's bill, which has been referred to committee there, saying that he was originally a supporter of euthanasia, thinking that adequate safeguards could make it a safe alternative for patients who did rationally want to end their lives. But he now feels that it is not possible to have sufficient safeguards to protect the vulnerable people who are killed without their knowledge or consent once the mentality that some lives are not worth living is made within the medical community.

Senator DI NATALE: Firstly, let me put on the record my support of palliative care and the important work that is done in that area.

Dr Best: Thank you.

Senator DI NATALE: I think it is absolutely critical. I do not think these two issues are mutually exclusive at all. I do not think you will find a person in the parliament who would not advocate for greater investment in palliative care and to ensure that people have access to the best possible palliative care available.

Let us go to that issue of knowing the patient. In psychiatry, people are seen for the very first time and assessments are made by psychiatrists on occasion to deprive them of their liberty—a very serious thing to do.

They may be deprived of their liberty and committed to a psychiatric institution. That is just done on the basis of one assessment, isn't it?

Dr Best: The initial assessment?

Senator DI NATALE: Yes.

Dr Best: Obviously, if they think they are a risk to themselves they will make the initial assessment on the first visit—yes.

Senator DI NATALE: So they have no knowledge of this person. They have never met them before. They make a decision on the basis of the initial assessment. Nothing could be more serious than a person being deprived—

Dr Best: Oh, yes, something could be more serious. Putting them to death is reversible. Whereas, if they are admitted, they do have a chance to have a second chat and decide 'I made a mistake.'

Senator DI NATALE: It is a very serious judgement to deprive someone of their liberty and to have them committed to a psychiatric institution on the basis of an assessment.

Dr Best: Yes, that is the current practice. I agree that is the current practice.

Senator DI NATALE: We make decisions that have impacts on the lives of people on the basis of an initial assessment. That is the nature of medicine, isn't it?

Dr Best: One makes the best assessment one can at the time the patient is there.

Senator DI NATALE: The referrals we make to consultants are made to people who have no knowledge or history of the patient and part of their job in that initial assessment is to conduct a thorough evaluation and then chart a course of action. So not having an existing relationship with the patient does not preclude a medical practitioner from making some important decisions that will impact on that patient and their family.

Dr Best: That is true, but I will refer you to one of the reports from the Oregon legislation that said that psychiatrists thought that they would require three visits before they could adequately assess a patient. As I am not a psychiatrist, I would refer to that research.

Senator DI NATALE: Yes. Let me ask you about the statement you made in your opening statement. I think it was from Reverend Davies; is that correct?

Dr Best: I was reading on his behalf, yes.

Senator DI NATALE: 'The doctor is the preserver of life' I think was the statement you used.

Dr Best: Certainly doctors are taught at medical school to aim to preserve life where possible, but not at any cost.

Senator DI NATALE: That is right, but I think his view was that this legislation is not consistent with the notion of the doctor as a preserver of life.

Dr Best: That is true. If you terminate someone's life, you are not preserving it.

Senator DI NATALE: Have you ever in palliative care given medication to somebody that has resulted in their death at a time earlier than would otherwise have occurred?

Dr Best: Can I put on record that there is extensive research in place—

Senator DI NATALE: No, I am just asking a straightforward question.

Dr Best: I want to put this on record. There is an extensive body of research now that shows that adequate doses of morphine, other analgesics and sedatives and in therapeutic doses do not shorten patient lives. In fact, the research of Philip Goode at Newcastle suggested that it may in fact prolong life.

Senator DI NATALE: I have asked you a straightforward question: have you ever given medication to a patient that you believe may have resulted in their death occurring earlier than otherwise would have occurred?

Dr Best: No.

Senator DI NATALE: It is unusual for a palliative care physician. Almost any other palliative care physician asked that question would at least answer that that is exactly what they do and they have done it often. The imperative is to relieve people of pain and suffering.

Dr Best: I recognise that it is widely believed—

Senator DI NATALE: Accepted within the medical community—your view is an unusual one, would you suggest?

Dr Best: I can give you a dozen research papers now that would show—

Senator DI NATALE: But would you suggest that that is an unusual view within the palliative care community?

Dr Best: No, not within the palliative care community. Within the medical community perhaps. Some doctors who say they have performed euthanasia do so because somebody died while taking morphine and they think it contributed. But within the palliative care community there is great frustration that it is considered that therapeutic doses of analgesics and sedatives will necessarily shorten life in the way that—

Senator DI NATALE: Not necessarily.

Dr Best: Pardon?

Senator DI NATALE: You used the words 'will necessarily shorten life', but they can.

Dr Best: There are very rare cases where in extreme distress some palliative care doctors may have given sedatives to relieve distress that make it difficult for someone to eat or drink in which case that would have shortened life. Personally I have not done that. I would say it is extremely rare. In the last hospice where I worked, where we would have about 600 admissions a year, perhaps two or three patients may have been that distressed, but, as I said, I am currently studying the phenomenon of suffering and I believe that there are alternative therapies that should be offered rather than just sedate the patient.

Senator DI NATALE: Who decides whether a patient is suffering?

Dr Best: The patient generally.

Senator DI NATALE: You made a statement earlier on about patients who were suffering. I think the language you used was that people may not avail themselves of all of the therapies that might be available and may not be aware of what is available and therefore are suffering needlessly. Is that—

Dr Best: Yes, certainly. One time when I was debating Dr Philip Nitschke, he had with him the wife of a gentleman who had gone to Switzerland and died under the arrangements there. I asked her what the problems had been and certainly one of his major problems was pain, and I said, 'Had he been to see a palliative care specialist?' and she said, 'He had been recommended to see a palliative care specialist but decided he didn't want to.' I would think that it is possible that his choice to go to Switzerland was not fully informed because he did not have the advantage of knowing what was possible in terms of treatment options. Certainly he had not experienced them.

Senator DI NATALE: What if, after all of those treatment options, she still considered the suffering intolerable?

Dr Best: I think that is quite possible, because in the jurisdictions where these things are legal—

Senator DI NATALE: No, I am not talking about that specific jurisdiction; I am just trying to tease out the ethical dimensions of the problem. Should someone avail themselves of all of the therapies that are available and still consider that—

Dr Best: What I am trying to explain to you is that existential suffering is not a physical problem that is treated with physical measures and that we are discovering, in our current research—

Senator DI NATALE: Are you saying that somebody who goes through a course or is involved in palliation and through that process is still experiencing significant physical distress, you said earlier it is—

Dr Best: It is very rare, yes.

Senator DI NATALE: It is rare and that is why the number of people who this legislation in practice would affect is very small and of course if—

Dr Best: I agree.

Senator DI NATALE: Many people who exercise the choice at some point to have the option to go and speak to a doctor and have voluntary assisted dying, many of them will choose not to do it because the palliative care route satisfies all of their concerns.

Dr Best: Absolutely.

Senator DI NATALE: So I think we accept that, but there are small numbers—

Dr Best: There is a very small number, yes.

Senator DI NATALE: for whom that just does not work, and they continue to have pain. I think to ignore that would be disingenuous.

Dr Best: I have the greatest of sympathy for those patients.

Senator DI NATALE: So ultimately it is that person who—and it is a tough call. Look, I am a physician and I have wrestled with this myself because, of course, this is ultimately something that goes counter to our training. But your point is that it is the patient who decides—

Dr Best: Yes.

Senator DI NATALE: and in those circumstances, who are we as physicians to deprive them of an option that would relieve them of their pain and suffering?

Dr Best: I have said there is a small number of people who have distress at the end of life, despite being treated in palliative care units, who are currently given sedation to cope with their problems. I agree, there is a very small number: less than one per cent of people who present in palliative care services, according to Sydney research, who request that.

Senator DI NATALE: We can argue about the numbers but, yes.

Dr Best: The reason I oppose and the archbishop opposes the legalisation of physician-assisted suicide in euthanasia is not there is nobody who rationally requests it after everything we have done for them is not enough. It is because we cannot believe that it can ever be safely legislated to the point where vulnerable people in the community will not be killed against their wishes, and that is the basis of our opposition. It is not because there is never anyone who rationally requests it.

Senator DI NATALE: You are accepting that the impact of your opposition to this bill is that there will be people who will die, who will experience tremendous pain and suffering that cannot be relieved through palliative care, but you believe that that is something that can be justified on the basis of what are the potential impacts—

Dr Best: I am doing a PhD on ways to relieve suffering—

Senator DI NATALE: I do not want to know about your PhD. I am just asking you about—

Dr Best: I do object to the way we talk about this hopeless suffering. There is always something we can do. We can stay with people—

Senator DI NATALE: Let us have an honest conversation about this. You have just admitted that there are people—

Dr Best: There are a very small number, yes, I agree.

Senator DI NATALE: It is ultimately the patient who is experiencing that pain and suffering.

Dr Best: That is right.

Senator DI NATALE: We do not have a right to judge whether those things are legitimate.

Dr Best: I do not judge them. I agree that there are a small number of people who rationally request euthanasia and physician-assisted suicide when all that we have offered them in palliative care is not sufficient.

Senator DI NATALE: Because they are experiencing severe pain and suffering.

Dr Best: But it is not the role of government to grant autonomy to everyone in our community. It needs to be balanced against the justice—

Senator DI NATALE: At the moment, government is stopping those people—

CHAIR: Senator Di Natale, let Dr Best finish.

Dr Best: who are vulnerable in the face this type of euthanasia and physician-assisted suicide, which is evident in all the jurisdictions where they have been legalised, including Oregon.

Senator DI NATALE: Do you accept that government criminalises that activity at the moment and prevents people from exercising that option?

Dr Best: Yes, of course, I agree. It is against the law. That is why we are here.

Senator DI NATALE: But you have just said that it is not the role of government.

Dr Best: The role of government is not to give everyone everything that they want. Some people want to break into shops and steal things. Just because somebody wants to do something does not mean that we are obliged to provide legislation.

Senator DI NATALE: You are comparing someone with end-stage cancer who cannot get relief from palliation to somebody who breaks into a shop. I am not sure how that analogy is—

Dr Best: We can give them relief. They just do not like the relief we give them.

Senator DI NATALE: That is a bit offensive if you do not mind.

Dr Best: I am offended by the suggestion that in palliative care units we do not ease the suffering of people at the end of life.

Senator DI NATALE: You have just admitted that there is a small group of people who will not have their symptoms relieved and who will continue to have severe pain and suffering despite our best efforts.

Dr Best: No, I said that at the moment we give them sedation which is not acceptable to them. The problem is not that there is not anything that we can do for them; the problem is that they are not happy with the solution that we have.

Senator DI NATALE: Well, that seems like a pretty big problem.

Dr Best: It is a problem. It is a huge problem for those people and I have the greatest of sympathy for them.

Senator DI NATALE: But that sympathy does not extend to allowing them the freedom to exercise the choices that they want to make at the end of their lives?

Dr Best: I agree that it is a very difficult equation, but I am so concerned for the people who would be at risk if this legislation were passed. It is because of the vulnerable people who are at risk of being killed without their knowledge or consent that I have very reluctantly had to say to people, who have said to my face that they want to be killed, that I am very sorry that we cannot do that for them. We will do everything we can for them, short of killing them, but in the Hippocratic oath, euthanasia is not what doctors are supposed to do.

CHAIR: This is a very interesting debate—almost. But we really have run out of time. Thank you very much for your attendance, Dr Best. Please thank the archbishop for his submission.

Dr Best: He does offer his apologies. He really wanted to be here.

CHAIR: I understand that. Thank you very much.

FROMMER, Mr Michael David, Policy Analyst, Australian Federation of AIDS Organisations

LAKE, Mr Robert James, Executive Director, Australian Federation of AIDS Organisations

[12:03]

CHAIR: Welcome, Mr Blake and Mr Frommer from AFAO and NAPWHA. The first is the Australian Federation of AIDS Organisations and the second, the group making the submission, is the organisation representing people living with AIDS in Australia. We have a submission from the two groups which we have numbered as submission No. 46. These are parliamentary proceedings and parliamentary privilege applies. If there is anything you want to say in confidence, please raise it with us and we can go in camera, if that is needed. If you want to amend your written statement or add to it, now is the time to do it. Otherwise, I will ask you to make a brief opening statement and then we will ask you some questions.

Mr Lake: Our submission is a joint submission on behalf of AFAO and NAPWHA. NAPWHA is a member organisation of our federation and is the National Association of People with HIV in Australia.

Thank you for the opportunity to make a submission to this inquiry. The main reason we submitted to this, and over many years have been actively engaged in debates like this, really is our experience as people with HIV and the experience of our community in relation to living with what for many years was an untreatable terminal illness and I suppose our history since that. Our submission really reflects that and reflects the experience, particularly in the first half of the epidemic, of people wanting to what we call self-deliver. That was frequently talked about when there were no drugs available. One of the factors that focuses our view on this is HIV is a transmissible condition so many times a person nursing their partner would be positive as well so they would know very clearly what possibly was going to be happening to them and people had networks and friends. So it was a very intensely felt experience.

As we have talked here, it is not like that any more. I want to unequivocally say that. We are informed by our history but, in terms of the notion of people themselves being able to have a chance to make a decision and seek support when they completely, rationally and individually feel they want to end their lives, we continue to support the discussion of that and the progress of that, but the salient point for us is about lives being valued. We also do a lot of work. We talk in terms of particularly older people with HIV now, people who had lived many years with HIV and are consequently experiencing a range of morbidities, very chronic ill health as well as cancers and things like that. They have really had 20 years of life like that. Our first point is always their quality of life—their access to health care, their access to support and their being valued.

I particularly note Senator Di Natale's idea that this is a last ditch thing. We are not here enthusiastically supporting this. We are here saying that there is a place for it. I know a range of other views about setting as many steps in place before getting to here—about ensuring that people have access to the services they need, whether it is about pain, psych support, a range of those kinds of things and even the costs of medications. All those things are preconditions before any of this can be considered. We reiterate that.

In our language I suppose this is consistent with what we have done all through the AIDS epidemic, which is about minimising harm and minimising the harm people in this situation would experience and that we know people have already. We do not want to go back there. We have made a couple of points in relation to some particular aspects of the bill itself around a person who can request the section 10. The other thing we are interested in is the notion of the range of views that come into play around the decision making—the significant clinical input into that and the notion of good psych evaluation in that situation. We are also thinking about the notion of social work type input because of someone's long-term poverty. We have had experiences where people have had homophobic bullying by neighbours. All of those sorts of things wear down their resistance and resilience to keep going on. That has nothing to do with them. Those are society's problems and are the things that need to be addressed.

I would like to note the importance of the submission from Craig Wallace entitled *Lives Worth Living*. This is about terminal illness and, again, lives being valued. We particularly support that submission about the need to focus on that and the way we often see the lives of people with disability being valued in different ways—particularly based on their experience of a life where they do not get the supports to live the life they can and make a decision on that basis. I want to note that we absolutely support those views.

I might stop there, if that is okay. It is interesting being here now. If we had been here 20 years ago, this room would have been full of people with HIV with an interest in this matter. We have moved on, but there are still people for whom this could have some relevance, since it could support them. We are most keen to see that the safeguards and the protections are there through the decision-making process.

Senator DI NATALE: I will address the issue of gender in the way the exposure draft is written. I think you can take it as read that those changes will be made. The next issue is the exclusion of people in rural, regional and remote communities.

Mr Lake: I think you are looking at the LGBTI Health Alliance submission?

Senator DI NATALE: I am, yes. I apologise, I am looking at the wrong submission. I will reserve that for that discussion. Let me ask you about the requirement for two doctors and a psychiatrist. The feedback is that, on the one hand, it is important to have these safeguards in place and, on the other, we are restricting access to a group of people. Where do you both sit on that issue?

Mr Lake: What do you mean when you say 'restricting access'?

Senator DI NATALE: Somebody who lives in the country cannot access two doctors and a psychiatrist very easily and therefore we are discriminating against that population. Do you have a view?

Mr Lake: It is interesting because the alliance submission talks about the role of telehealth and things like that. Not being able to see doctors et cetera is not just a rural and remote issue. I think it is an important safeguard. I would assume that, as a benchmark, it would not be able to progress. If a person cannot get access to those people, then this is not a good process to even begin with.

Senator DI NATALE: The flipside of that is that, if we were to remove the requirement to have an assessment from a psychiatrist, the concern is that there may be people who have depression that is not picked up by the GP who then are able to access this.

Mr Lake: I would say that a psyche assessment is something that, in this case, has got to be a part of it.

Senator DI NATALE: You think it is important?

Mr Lake: Absolutely.

Senator DI NATALE: Even if that means it is going to be a little more difficult to access a psychiatrist?

Mr Lake: Yes, absolutely. If it calls for other support to make that happen and not just, as I think has been talked a bit about, the opportunity for a psychiatrist to make a reasonable assessment. And context is often one of the key things.

Senator DI NATALE: What about the definition of 'terminal illness'? We have had different views. At one end of the spectrum it should not just include people with a terminal illness; it should include people with a medical condition. We should not restrict it to people with a terminal illness. At the other end of the spectrum we really need to tighten that definition and, in fact, put in something like a time frame. How do you feel about that? Do you feel that the definition, as it is written, is appropriate, which is effectively saying that someone with a terminal illness is able to access physician-assisted dying?

Mr Frommer: I understand that was raised by a previous witness. I think the difficulty is perhaps in them defining the period of time. If it had to be immediate, you get into other complicated discussions about at what point the imminence of their inevitable death, which is what it is premised on, is clear. It is an interesting question. I do not think there is a simple answer. If you put in a time frame, it is not clear what the appropriate time frame would be.

Senator DI NATALE: You think it should be at the discretion of the doctor to make that judgement?

Mr Lake: I think so, but in terms of the notion of illness moving out and out into condition, I think this is principally a medical bill—a clinical situation. I think that keeping those constraints on it is important.

Senator DI NATALE: You do not think it is appropriate that the definition of 'terminal illness' be changed to 'terminal illness and a medical condition'? That is one of the suggestions from other witnesses.

Mr Lake: In our consideration of it, that has not been a factor for us.

Senator KETTER: I put to you the situation that, if we were to legislate to allow voluntary euthanasia—and I accept that HIV does not appear to be a terminal illness, from what you are saying, but there are co-morbidities which apply and which impact on people's lives—then, once the option of voluntary euthanasia becomes available, there will be ongoing pressure on people to consider that as a choice.

Mr Lake: The notion of the people around—carers, partners and so on—creating pressure, particularly for elderly people—that is a fact and that is what happens now. The protections against that have to be very strong. If this is going to be a person's decision, it has to be an unfettered decision. Obviously it will be unfettered in the sense of there being no actual abuse, but the emotional or financial pressures, or the pressure of possible withdrawal of support and such things, that can be brought to bear in these sorts of situation—there has to be protection from that. There are protection services—elders abuse services, for example—which are there for that,

which are there to offer protections for people who are in care and whose independence is limited. Being able to access those external inputs is important.

Senator KETTER: There would be some who would argue that as a society we should be supporting people to live rather than supporting people to die.

Mr Lake: Absolutely. We are not the cheer squad for this legislation, but I have known people, over the last 20 years, who have done this and I have known cases where it went badly wrong. I do not know people now who do it, but I know it happens. That is why we are here, so that there are some protections for those people. Where someone just says, 'Okay', clearly they have fallen through the gaps, so the issue is what we can do about that. Once we have acknowledged all that and once we have tried the supports—the pain management, the psychiatric support and all of those things—and they still strongly have that view, it should be a choice available to them. We fought a long time for the health of people with HIV—we are not abandoning people to die. We feel that very strongly.

Senator KETTER: I would have thought that people suffering with HIV would be in that category of being very vulnerable to pressure to take that option.

Mr Lake: Some people are, and that is why the protections need to be there. But many people are not. Many people are strong. They have had 20 years of strong self-advocacy and health advocacy and know that, if they get to these decisions, they will be informed decisions. In terms of people who are vulnerable to pressure—to withdrawal of supports and care—there should be nothing that lets this happen in those sorts of situations.

Senator KETTER: You mentioned that there are people who are strong and who can resist that pressure, but we have to consider the people who are weak.

Mr Lake: Yes, so the balance of protection needs to be there—absolutely.

Senator KETTER: Are you familiar with the debate about the way the media treats this issue of euthanasia and public attitudes towards euthanasia and the fact that the media seems to portray euthanasia as simply a matter of choice?

Mr Lake: I think the media reflects the debate. Some media reflects it as that; other media do not. I have seen bits of the debate in the media, yes.

Senator KETTER: Would you agree that it is a highly complex area?

Mr Lake: Absolutely.

Senator KETTER: You mentioned earlier your experience of situations that had gone terribly wrong. Are you able to share that information?

Mr Lake: Really just people who had to do it themselves. Doctors were terrified of getting involved in this sort of stuff. There were people trying to find out what worked. That is the sort of scenario. We had that around the world. In many of the cities where there were large communities of people with HIV—particularly in the US, the UK and here—the communities were connected and were supporting each other all the way through.

Senator KETTER: Those would be examples of people in distress, I would imagine.

Mr Lake: Yes, people in distress. At that point there were no medical treatments—the average time I think from diagnosis to death was about two years—and, depending on the sort of condition people had, they could be very awful deaths. That is not how it is now. That is what is advising us and not wanting that to happen. That is all I can say. That is our experience and what informs our work. As I said, we are here because this continues to be a debate in our community as well, but in a different sort of way.

Senator KETTER: To what extent is palliative care an issue that you have taken up for your community?

Mr Lake: It is huge. Palliative care has been a very valuable part of end of life care. There used to be a whole ward set aside at St Vincent's in Sydney just for palliative care for people with AIDS. That does not exist now because there is no that need for it. The experience of palliative care is good. We are talking about a very small group of people who would have made these choices. Many people wanted every bit of life that they could get, and palliative care and all of those supports to get that were really significant.

Senator KETTER: Are you familiar with any of the jurisdictions overseas where—

Mr Lake: Not really. I suppose the Swiss group—I am not familiar with the Dutch legislation that has been referred to, or the US legislation either.

Senator KETTER: Thank you, Chair.

CHAIR: At the beginning, I think you said 20 years ago the room would have been full of HIV sufferers, who would have had a very—

Mr Lake: Who were very actively engaged in these sorts of debates. People were very actively engaged in them. The notion of this then—you probably would have had GPs here as well.

CHAIR: But on the basis that they were incurable and therefore, 'How can we get out of it?'. The fact that 20 years later those people are still here perhaps sends some sort of a message about this.

In your organisation and in the wider community that you are involved with, would it be fair to say that people who want to have euthanasia have that option now by suicide of some form, which is relatively easy, I guess, in some areas?

Mr Lake: I am very hesitant to go down that sort of path because I think that the distress suicide causes—not just to that person about how they end their life but to the people around them—is huge. And so—

CHAIR: But one of the arguments for this bill—and I am taking a very neutral position at the moment—is that you do this in this way and it relieves the stress on the family.

Mr Lake: And that it is a considered decision; the family has talked about it and those sorts of things.

CHAIR: Yes.

Mr Lake: That is the best-world scenario where that happens; everyone is agreeing with it and they have talked through. That will probably be a very small group of people and that would be a reasonable thing. It is a very complex issue because of the interplay around the medical condition that is leading one to want to make this decision and all of the other things—care, being absent, being valued and all those other things. It just has to be such a considered decision. I am just really aware of that.

The other thing that our community experiences in disproportionate things is suicide. I go back to my first thing, which is about valued lives. Whether it is young gay men, young lesbians or whatever—for us, valued lives is one of the critical things.

CHAIR: I can see where the topic is somewhat confronting—

Mr Lake: It is.

CHAIR: I am just trying to say, 'People do it now; which is the best way to do it if you are going to do it?' But if you would rather not take that further—

Mr Lake: No—I am just not quite sure. It is a personal experience. A friend of mine suicided earlier in the year. He had HIV for a very long time. He had also had a major thing—he had a range of things going on for him—and then he was diagnosed with Parkinson's. It was one of those things where it was very planned and very considered. He talked about it with his family and everyone like that. But, again, every one of us were very distressed. He had just got to the end of it for him.

CHAIR: It is a question in a situation like that of 'Which is better of two not-very-nice options?'

Mr Lake: Absolutely, yes. The judgement was up to him, doing that.

CHAIR: Okay. If nobody else has any questions all I can do is thank you both very much for coming along—for your assistance and for your submission as well. We appreciate your help.

Mr Lake: Thank you very much.

HIGSON, Ms Shayne, Christians Supporting Choice for Voluntary Euthanasia**WILLIAMS, Mr Geoffrey Kerr, Member, Christians Supporting Choice for Voluntary Euthanasia**

[12:30]

CHAIR: Thank you very much for your attendance. We very much appreciate you coming along. I think you were here earlier and heard my obligatory warnings, so I am not going to go through them again. Thank you for your submission. We have numbered it as submission 86. Do you want to make any amendments or alterations to that?

Mr Williams: No, thanks.

CHAIR: Then I will ask you to make a short opening statement and we will then ask you some questions.

Mr Williams: I am a member of Christians Supporting Choice for Voluntary Euthanasia and the son-in-law of co-founder and national coordinator, Ian Wood, who was unable to attend today as he is travelling back from overseas and sends his apologies. He was a guest speaker at the world right-to-die society international congress. Thank you very much for giving Christians Supporting Choice for Voluntary Euthanasia, C4VE, the opportunity to give evidence at this inquiry.

Our organisation has about 1,200 members from across all states and territories of Australia. The objectives of C4VE are on the back cover of our booklet I have tendered, entitled *I want the choice of a peaceful death*. The booklet provides succinct arguments that our organisation has prepared to explain why we believe that the relatively few desperate terminally ill patients who are suffering intolerable physical or mental pain and anguish which cannot be adequately palliated should be given the right to legally request medical assistance to end their suffering.

The other item I have tendered this morning is a summary of the Newspoll national survey of 2,521 voters in late 2012 on behalf of YourLastRight, the umbrella organisation of all the right-to-die lobbying organisations in Australia. It updates the public opinion information on page 12 of the booklet. The question asked in that survey that prompted the results on the graph that I have presented was: 'Thinking now about voluntary euthanasia, if a hopelessly ill patient experiencing unrelievable suffering with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to provide a lethal dose?' That survey gives you the answers and national public opinion on that question.

There are three fundamental issues that C4VE wants to emphasise in the discussions about the exposure draft. Euthanasia is not a case of life or death but a choice between different ways of dying. On that, I refer you to page 14 of our booklet. The second major point is that the vast majority—82 per cent overall—of voters, many of whom align themselves with the various Christian denominations, answered 'yes' when asked the relevant question in the 2012 Newspoll. This majority support is higher than even the major political parties could ever dream of achieving. Support of this magnitude could be described in political terms as a landslide, if not an avalanche! The third point I want to make is that there is significant theological support for the introduction of similar legislation in many jurisdictions around the world. Former Archbishop of Canterbury, Lord Carey of Clifton, recently changed his mind, having previously been against it, and has given his public support to the bill introduced into the House of Lords by Lord Falconer. In the *Daily Mail* in July Lord Carey wrote:

The fact is that I have changed my mind. The old philosophical certainties have collapsed in the face of the reality of needless suffering.

He said that it was the case of a man who had locked-in syndrome who had the deepest influence on his decision. I will pass on those with the internet link to that source. Another prominent Anglican supporter of VE is Archbishop Desmond Tutu, former Archbishop of Cape Town. In an article in *The Guardian* on 12 July this year he said:

A dignified death is our right—I am in favour of assisted dying. Nelson Mandela's passing was an affront. I spent my life working for dignity for the living. I now wish to apply my mind to the issue of dignity for the dying.

Another theologian in favour of VE is Hans Kung, a Swiss Roman Catholic priest, theologian and author. He has been the President of the Foundation for a Global Ethic since 1995. He was Professor of Ecumenical Theology at the use of the University of Tubingen from 1979 and has been Emeritus Professor since 1996.

There are prominent theologians who oppose the legislation. We commented on the stance taken by Cardinal George Pell and the Anglican Archdiocese of Sydney in which I live on page 5 of our submission. It is polite, at best, to say that their comments are misleading. Anyone would think that they genuinely believe that we are talking about compulsory euthanasia. The introduction of this proposed bill will not impose in any way on the lives of those opposed to the legislation nor upon the lives of such vulnerable people as the aged and disabled,

unless they meet the criteria carefully established in the exposure draft and specifically request assistance to die with dignity. However, the continued opposition to VE legislation does impact mightily on the lives of those poor souls who desperately need the right to die in peace with dignity. Church leaders, who are often the loudest opponents of VE, are more intent on adhering to their religious dogma and less interested in showing love and compassion for the truly vulnerable in our society—those proportionately very few terminally ill patients for whom palliative care does not ease the pain.

We respect the rights of people to disagree with our point of view and there will no doubt be loud objections to my comments. We politely request that opponents of VE equally respect our genuinely held opinion, which, we remind them, is shared by the significant majority of voters nationally. Former New South Wales Premier Barry O'Farrell publicly stated that the members of his government would be given a conscience vote on a similar bill introduced into the Legislative Council of New South Wales in 2013. However, not one of the government's MLCs voted in favour of the bill and one member even tearfully abstained because of a recent family death, where the issue of voluntary euthanasia was relevant. It is clear that democracy is not working in New South Wales—nor is it working in Tasmania or South Australia, where other VE legislation has been voted down in recent years.

We implore the senators who are going to debate and vote on this legislation to hear that wishes of the vast national majority of voters and introduce this long-awaited proposed Commonwealth legislation that will allow all terminally ill Australians the right to choose if they want to request medical assistance to die. It will not affect anyone else. Not to heed our polite request would be quite simply undemocratic as well as untheological, dispassionate and illogical.

CHAIR: He is you very much, Mr Williams. Ms Higson, did you want to say anything additional at this stage?

Ms Higson: No, I think that covers it.

CHAIR: As politicians we know about opinion polls. You can almost get any result you want from an opinion poll if you frame the question correctly. I suspect a differently framed question on this subject could equally get the same results. But added that bit of trivia to an otherwise very sensible debate, can I just refer to that opinion poll where it talks about experiencing 'unrelievable suffering'. I would suggest that the opponents of euthanasia would suggest that there really isn't any suffering that cannot be relieved.

Mr Williams: I have read a book by palliative care nurse in England by the name of Julia Lawton, whose reference is in our submission, which is quite graphic about some of the terrible discomfort, indignity and the stench of sickness in some palliative care wards. I think we have agreed before that there are always going to be a handful proportionally who might require this legislation, and that is as it should be. But why, we think, should such people suffer because of other people's attitudes when it is none of their business in our mind.

Ms Higson: This morning COTA spoke about their members. Last year they held a parliamentary forum in New South Wales called 'Let's Talk about Dying'. In the lead-up to that they did a survey of their members and they asked whether people in the survey had had an experience with palliative care and, if so, where they happy, did it provide a comfortable death for their loved ones. Over 26 per cent—26.3 per cent, I think, because I do not have it in front of me because I was not expecting to have to refer to it—said no, they were not. That is quite a large amount of people for whom it didn't.

I can also speak from my own experience. My mother died of an aggressive brain cancer at the end of 2012. She had the very best palliative care. I get quite upset, obviously, because it is still a very traumatic time. I took care of my mum full-time for seven months through her illness. She knew right from the beginning that there was nothing that doctors could do to save her life. Brain cancer, as you would all be aware, is one of the really nasty ones. But she loved life so she wanted to hang on for as long as possible. They could not operate, they could not to radiation therapy, because she had multiple brain tumours.

She was referred when she left hospital to palliative care and had top-quality palliative care community, because we had family that was able to take care of mum at home as her condition deteriorated. But right at the beginning when she got her prognosis, she asked the neurologist, 'Will you look after me in the end?' She sort of smiled and said, 'You know what I mean—before it gets ugly.' She was obviously worried about the end and I am sure that part of that worry was the effect that it would have on myself, her partner and my two sisters—not to mention the five grandchildren who just adored my mother.

It is not right to say that there is palliative care that can alleviate all suffering. She suffered a lot at the end of her life. She only really asked or pleaded with me to end that suffering about 15 days before she did finally pass away. I had promised her in the beginning that I would not let her suffer. I thought that under the current system

that that would be possible. We had the best doctors—St Vincent's Hospital Sacred Heart Hospice. It should be achievable. But I now know, because of all the other experiences that I have heard about, that it is still not possible in all cases, particularly pancreatic cancer and that sort of thing. Brain cancer is different; the suffering is different. I know that there isn't time to go into all of that. The final option that mum was given—terminal sedation—did not mean that her end was dignified, peaceful. I am happy to answer in more detail, but I am just aware of the time.

CHAIR: I suspect that there are many with similar experiences. Neither of you are doctors. We have had doctors. Perhaps Senator Di Natale might help. I do not want to trivialise the debate, but I once had morphine, when I had a heart operation—a valve put into my heart. It seemed to me to be pretty good, that morphine. I would have thought it cured everything! Is that not correct?

Senator DI NATALE: No, not always. It is not just about the physical suffering. There is incontinence and all sorts of other things that go with it.

Mr Williams: If I may comment on that, Senator. There is a sadly departed woman in France by the name of Chantal Sebire. I forgot to hand this up earlier. It is in our submission, but I want to hand it up because it is a bigger picture and a bit more graphic. It does not say it on there, but my understanding is that she was allergic to morphine and other medicines. She was not able to get the palliative support she needed. She begged the president of France at the time, Sarkozy, for permission to die, but it was refused. She eventually, I think, had to go to Switzerland for relief.

Senator KETTER: Mr Williams, you have mentioned that you have 1,200 members.

Mr Williams: About 2½ thousand. I think that is it—2,521.

Senator KETTER: Sorry, I must have written down the wrong figure.

Mr Williams: No, I am very sorry; I am getting the numbers of the survey and the numbers of my membership confused. We have 1,200 members of Christians Supporting Choice for Voluntary Euthanasia and the survey was 2½ thousand. I beg your pardon.

Senator KETTER: I note in the document you have handed up, Christians Supporting Choice for Voluntary Euthanasia opens up membership to non-Christians and ex-Christians.

Mr Williams: Yes.

Senator KETTER: Would those people constitute part of the 1,200?

Mr Williams: They do, yes. My understanding is that 80 per cent of the 1,200 are active Christians. The majority of the remainder are lapsed Christians who have left the church in disgust because of the church's attitude to this issue. And there are some atheists, who support the cause but who are not Christian. I beg your pardon; I should have clarified that sooner. Thank you.

Senator KETTER: That is all right.

Mr Williams: It still a relatively relevant number to support our cause.

Senator KETTER: Yes, it is a number. It is bit unusual for atheists to be wanting to be members of a Christian organisation.

Mr Williams: Yes. That is because we share a common aim.

Senator KETTER: Okay. I have a passing acquaintance with Christianity, and I am familiar with the Ten Commandments. I note you make reference to the fifth commandment in your submission.

Mr Williams: Thou shalt not kill.

Senator KETTER: You argue that that is irrelevant?

Mr Williams: No, not irrelevant; I think it is misunderstood. My understanding of the theology—and I have only read a little bit; I am no theologian myself—is that the original Hebrew interpretation of that commandment is, 'Thou shalt not kill unlawfully.' Otherwise, it would not be possible, in my opinion, for popes and other church leaders to send their parishioners off to war, if there were no possible way of saying that in some situations it is okay to kill. I think it is a very valid point that you raise, thank you.

Senator KETTER: Would you agree with the principle of what some Christians call the sanctity of human life?

Mr Williams: Yes. I agree with the sanctity of life if the person themselves does not want to die.

Senator KETTER: Do you also agree with another Christian principle that life is a gift from God?

Mr Williams: Yes. It is a gift of God, but we have been given free will to make choices in our lives and will answer at Judgment Day, if you believe in Judgment Day. For atheists, there are no consequences at all, but Christians believe: 'I make choices in my life; I will answer to God at the end of my life for the choices I have made.' God did not put us on earth as puppets. He gave us free will to choose whether or not to believe in him or her.

Senator KETTER: All Christians, presumably, believe in God.

Mr Williams: That is right. My point is that there are lots of different Christian denominations. They are such because over the years they have disagreed fundamentally about some basic tenets of the Christian creed. They cannot agree amongst themselves as a group to have one true, inviolable fact about what the faith proves. It is faith because you cannot prove it. My attitude is: why should Christians, because they have this faith, be able to impose on someone who does not have the faith or has a different faith with a different point of view, be able to say: 'My opinion is more important than your opinion. I'm in a better position to know what is better for you than you are. Therefore if you are suffering, that's very sad, but we can't bring in a law to change the situation so you can have an opportunity to choose medical assistance in dying.' That will open up the floodgates, and 'Thou shalt not kill' and 'My opinion is more important than yours'—

Senator KETTER: You agreed with me a moment ago about the concept of the sanctity of human life?

Mr Williams: Yes, but we are talking about death not life. We are talking about two different ways of dying. We are not talking about continuing to live. We are just trying to work out how you are going to die as peacefully and as humanely as possible. We treat our animals better than we treat some terminally ill patients.

Senator KETTER: How do you interpret the word 'sanctity'?

Mr Williams: No-one has the right to take away another person's life.

Senator KETTER: I would agree with that.

Mr Williams: But we have already agreed that suicide is not illegal, but it is illegal to assist someone to suicide. Where is the logic in that?

Senator KETTER: You have just said that nobody has the right to take another person's life?

Mr Williams: That is right. Suicide is not a crime, but the assistance of a suicide is a crime. It is not a killing. The person is begging, begging for relief of their intolerable pain. Some religious dogmatic idealists are trying to say, 'My ideal is more important than yours; you shall suffer tortuously for the rest of your life, however long that might be—weeks, days, months—because I do not think the law should change to allow for this humane end of life.'

Senator KETTER: You would agree that Christians have the right to advocate for changes to the law or for the law to stay as it is?

Mr Williams: As I said, I agree that everyone has a right to a different opinion. But the point I am making is that, by introducing this legislation, it will not impact on those who oppose it. But by not introducing it, listening to what I believe to be, generally, a significant minority in our society, for fear of offending religious niceties, it is going to bring a terrible impact on those very few people, who, it has been agreed already, will be the ones who benefit from this legislation. I cannot see any logical problem in having a law which says: 'If you are really desperately sick and you cannot bear to live any longer, then we are going to give you the option to have a peaceful pill or whatever.'

Senator KETTER: We talked about your newpoll. Are you familiar with other polls that have been taken overseas in relation to euthanasia?

Mr Williams: I can't off the top of my head say that I do know.

Senator KETTER: I am aware of a poll conducted in the UK, by Comres/CARE, which showed that, once people were informed about the arguments on euthanasia, that that figure of support drops right away. You are not familiar with that?

Mr Williams: I am not familiar with that. What was the question asked?

Senator KETTER: You are not aware of it so—

Mr Williams: That is why I deliberately put into my submission the question that was asked for that poll, so there is no doubt as to exactly what it is that people were saying yes to. A lot of people can say, 'There's a poll overseas' but, unless you know what the question was that was asked and in what context, I cannot comment on it. However, can I comment on the changes in palliative care over time. In 1961 my grandfather had prostate cancer and he was begging his doctor, who happened to be my other grandfather—just to add a bit of spice to the family

dynamic—for more morphine to keep him out of pain. In those days the attitude was: 'We can't give you too much morphine because you might become addicted.' I have spoken to Professor Ken Hillman, the Professor of Intensive Care at Sydney University, and he has said that the current understanding is that if you are given enough analgesic to prevent pain, but no more, then you will not become addicted to it. Is that correct, Senator Di Natale?

Senator DI NATALE: It takes a lot of effort to become addicted to morphine. People do not get addicted from a few doses. It is hard work.

Mr Williams: My point is that at the time that was the understanding of palliative care. Fifty years ago my grandfather suffered great pain because the medical profession and society said, 'We can't give you any more because you might become addicted.' If he becomes addicted, so what? He was not going to live for long anyway and so what does it matter if he becomes addicted? But that was the attitude in society at the time. My point is that attitudes now are moving within palliative care—which is a relief—but they are not moving quickly enough in our opinion to support those desperately few.

Senator KETTER: You made a comment at the outset of your submission that we are not debating life versus death here; we are debating different ways of dying.

Mr Williams: That is right.

Senator KETTER: I presume we are talking about terminal illnesses—

Mr Williams: That is right.

Senator KETTER: Previous witnesses have talked about the possibility of being diagnosed as terminal but having different time frames for survival. We have also heard about the AIDs community where what was once seen as a death sentence can now be managed over a longer period of time. We are talking about people continuing to live versus people dying. What is your response to that?

Mr Williams: No-one wants to die earlier than they have to, but if someone is suffering so much that every waking day is torture for them, what is the point of living longer? I understand—and it might have been mentioned in one of the earlier sessions—that of those overseas who are given the medication or the rights to take the medication only 19 per cent in Oregon actually take it. Just having the peace of mind to know that, as you near your end, you are not going to suffer, because when it gets too much and you dread waking up in the morning. When it gets to that stage, you will have the pill to immediately end the suffering, and that then allows you to free up all your emotional energy into enjoying the rest of your productive life. Eighty per cent of those who are given the medication never use it, and that is of the very small percentage who qualify for the right-to-die assistance. I simply cannot see the logic in denying this legislation.

Senator KETTER: I think the logic is that there are vulnerable people who might be affected and have pressure placed on them—

Mr Williams: I understand from the legislation that you have to satisfy two doctors and a psychiatrist that it is not just depression that is causing you to take this course and that it is not pressure. I think two doctors and a psychiatrist should know whether there is pressure or genuine pain. From my understanding, in Oregon they have had this legislation for 17 years and they have done studies which have shown that this slippery slope you are referring to does not exist. It is a scaremongering tool used by those who are ideologically opposed to the proposed legislation and who will do anything they can to stop the law. We in Christians Supporting Choice side with loving compassion and mercy and not with religious dogmatic adherence to a particular point of view.

Senator DI NATALE: I will not get into a theological argument with you. As a lapsed Catholic I probably do not have much to offer there. But let me talk to you about some of the specifics of the bill. You have dealt with the slippery slope argument. I was going to ask you about that, but I think you have just dealt with that. Is there any evidence, in your view, that highlights that it is something we should be concerned about?

Mr Williams: My understanding is that Mr Richard Mills, past president of Dying with Dignity NSW, made a submission to this inquiry which addresses that issue quite well. If you do not already have it, we have a copy of it here.

Senator DI NATALE: No, we have that submission. I just thought there might be something you wanted to say in your own words.

Mr Williams: There are studies overseas that I am aware of which absolutely debunk—

Senator DI NATALE: Dismiss the argument?

Mr Williams: any of these scaremongering tactics used. There is no slippery slope.

Senator DI NATALE: The Newspoll, I think, is pretty hard to argue with; the question is straightforward and it is consistent with a number of other polls that have been done. But the number of Anglicans who support it is actually higher than the general population.

Mr Williams: That is right.

Senator DI NATALE: I thought that was interesting, particularly given that we had heard evidence from the Sydney diocese that obviously was not consistent with the views of most Anglicans.

Mr Williams: That is right.

Senator DI NATALE: The argument, on the one hand, is that we have vulnerable people who may fall prey to others under the legislation; on the other hand, we have people who are suffering and all we can offer them is, basically, terminal sedation and starvation.

Mr Williams: That is how my wife's grandmother died, by the way. She starved to death in an Australian nursing home, in Adelaide. Her care was excellent, but she starved to death over three weeks. She had been a vegetable and uncommunicative for three years, or two years at least, in a comfy day chair. Her life was just—well, I cannot imagine what it is like to have Alzheimer's. Two days ago I was diagnosed with—

Senator DI NATALE: But of course this legislation would not change that.

Mr Williams: That is the point I am making. I was under the impression that by not having a time limit between the time of diagnosis and the time when you actually die—

Senator DI NATALE: You have to be mentally capable of making the decision.

Mr Williams: Therefore, why can't someone who is sane make that decision, like my mother was until 2009? She was diagnosed with Alzheimer's in about 2001. She now does not know who I am, does not know who Dad is; he has been grieving for 13 years—not quite that long, because it was only five years ago that she got to the stage when she did not recognise him anymore. She used to go around the house muttering, 'God, take me now,' because she was brought up a very strict Methodist. She used to wander around saying, 'God, take me now,' but he did not and she now has to suffer.

Senator DI NATALE: Yes. I suppose the point is that, if somebody is in that situation, they are not able to make that decision of their own volition.

Mr Williams: That is why, as I said, I took heart when reading the law that you had drafted, thinking that by not saying that you have to be terminally ill, diagnosed to die within six months—

Senator DI NATALE: Let's talk about some of those specifics. You would prefer that there not be a time limit after diagnosis of a terminal illness.

Mr Williams: Definitely. Please, do not put a time limit on it, because, as it is now, I believe that it does open it up for people in the early stages of Alzheimer's.

Senator DI NATALE: Okay.

Mr Williams: I can give you an example of a case where a fellow diagnosed himself as having Alzheimer's. He is my niece's grandfather-in-law. He found himself driving in the wrong area, and then a few other things started happening. He realised, because he was in his 70s, 'I'm starting to lose it.' So he put his affairs in order, got a new, smaller car, made sure his wife was sorted out and then jumped off a cliff. Now, he probably had several years of good-quality life left before he got to the stage where he was no longer aware of what was happening around him. But he so feared Alzheimer's, or whatever cause of dementia it was, that he committed suicide far earlier than he otherwise would have. I believe a lot of the suicides by the aged in our society that we read about are by people trying to control their death, rather than relying on palliative care specialists who might or might not have sympathy for their plea to help them die.

Senator DI NATALE: Do you have a view that it should be expanded beyond people who have a terminal illness?

Mr Williams: I do. I do not think it should.

Senator DI NATALE: You don't think it should?

Mr Williams: I do not think it should.

Senator DI NATALE: You think it should be restricted to people with a terminal illness?

Mr Williams: Yes.

Senator DI NATALE: One of the witnesses we heard from earlier said that, if somebody has a number of chronic conditions and they are impacting on their quality of life, then—

Mr Williams: Sorry, yes. Maybe we need to clarify what you mean by 'terminal'—for example, if someone has locked-in syndrome, which was the issue that made the former Archbishop of Canterbury, George Carey, change his mind.

What about someone with motor neurone disease or multiple sclerosis in the advanced stages, like Loredana Mulhall, who was a candidate for the Senate last year. She is a complete vegetable. She can only do things by blowing into a straw. She can speak but that is about it.

Ms Higson: Can I just say, not a vegetable. When that term is used it usually means the brain is gone.

Mr Williams: Okay, quadriplegic I should say. Loredana is known as a quadriplegic and has to have help to do everything. She does not yet want to die, but she wants to know that, when the time comes when she cannot bear it anymore, she has the right to choose the method of her own death. What right does anyone else have to stop her? That is our opinion.

Senator DI NATALE: What about the requirement for two doctors and a psychiatrist?

Mr Williams: I think that is a good safeguard to ensure there is not anyone who is just depressed.

Senator DI NATALE: One of the arguments against that is access. People in regional communities are restricted because they do not have the same level of access to medical professionals.

Mr Williams: I had not thought of that. But it would seem unfair that a lot of people in areas where they do have access—I guess it is a case of discriminating against some people because other people can do something. At the moment no-one who is on the verge of death—

Senator DI NATALE: But do you think it is an important safeguard to have the psychiatrist involved?

Mr Williams: I do. I think it is aimed to stop people being pressured into dying, because they do not want to be an imposition on the carers. But probably, if you asked their carers, they would be quite willing to continue caring. My father cared for mum until he was no longer physically able to when he was in his late eighties. She had to go into care because when he had an afternoon sleep, because he was exhausted, she would go off wandering around the community. The neighbours would have to bring her home.

CHAIR: Thank you very much, Mr Williams and Ms Higson, for your assistance and for your submission. We very much appreciate that.

Proceedings suspended from 13:07 to 13:47

ANSARA, Dr Y. Gavriel, Manager, Research and Policy, National LGBTI Health Alliance

Evidence was taken via teleconference—

CHAIR: Welcome. Dr Ansara, we appreciate your being with us. We have received a submission from you, which we have numbered as submission No. 90. If there is anything that you want to alter in that submission, you could let us know about that now; otherwise, we invite to make a brief opening statement and then we will go to questions.

Dr Ansara: I will tell you a bit about the National LGBTI Health Alliance and then I will tell you about my role at the alliance. The alliance was formed in 2007 and the National LGBTI Health Alliance is Australia's national peak health organisation, working to improve the health and wellbeing of lesbian, gay, bisexual, transgender and intersex people and other sexuality and gender diverse or LGBTI people. We support measures which contribute to improved health and wellbeing by LGBTI Australians. The alliance provides a representative national voice on LGBTI inclusive policy development and service provision and also on evidence based decision making through LGBTI inclusive research and data collection.

My role at the alliance is that I am the manager of research and policy. As part of that role I manage the Alliance's research and policy portfolios and also handle submissions on a wide variety of health related issues that affect the distinct but sometimes overlapping populations that we call LGBTI. I have worked on these issues both within Australia and overseas and I have completed my PhD in psychology. On behalf of a hospital psychiatric team I have conducted training for hospital nursing staff that addresses the psychosocial support needs of people receiving services in in-patient settings, including people who have life-limiting conditions and people who have chronic conditions that might be considered terminal. In my prior work as a psychiatric rehabilitation caseworker and hospital volunteer I provided direct psychosocial support to people on an inpatient ward, some of whom received palliative care and were faced with very difficult decisions about how they would manage their pain and suffering for themselves and for people whom they had designated as family, as well as painful choices about how they wished to live and die.

Thank you for inviting me and us, the Alliance, here today to speak with you about the needs of LGBTI Australians who are facing these difficult choices. I want to start by saying that LGBTI people are part of the general Australian population and although this may seem like a very simple statement, I think it is one that is worth noting. There are LGBTI people in every religious group in Australia including in those religious groups that may not publicly acknowledge or welcome their presence as well as in those that do. Given that end-of-life decisions are a spiritual matter for many people, this diversity is very important.

In addition to that spiritual diversity among LGBTI people, our member organisations have very diverse views regarding the rights of mentally competent adults who experience extreme suffering due to illnesses that are considered terminal to end their lives in a manner they consider to be peaceful, humane and dignified. Our member organisations have different ideas about what that looks like.

Our member organisations also hold a diversity of views about whether medical practitioners should be permitted to provide such services and, if not, whether medical practitioners who provide these services should be granted immunity from civil, criminal and disciplinary proceedings. Those member organisations that do believe that penalties should apply for medical practitioners also hold a variety of views regarding the nature and extent of penalties that should be applied.

For this reason, I want to make it very clear to the committee that the alliance has chosen not to take a specific position regarding whether or not a bill such as this one should or should not pass. Instead we have chosen to focus on our shared areas of concern regarding end-of-life care for LGBTI people and their designated families. We base the concerns that we will raise with you on feedback we have received from LGBTI people, communities and organisations, including our member organisations across Australia.

We also note that the emergence of the current bill in the federal legislative landscape signals that there is increasing prominence of end-of-life issues in national policy debates in Australia, so evidently there is a need for clear policies in this area. Regardless of the specific nature of that federal legislation, whether the resulting legislation ends up promoting or prohibiting giving assistance to people who wish to end their lives, we believe that either way there are five key areas of concern that any legislation in this area will need to address to adequately ensure that LGBTI people are included, and to safeguard the welfare of LGBTI people and their designated families—that is, the people they consider family.

These issues were mentioned in our submission, and just to give you a brief understanding of what we are talking about they are: the exclusion of people of non-binary genders—people who do not identify as women or men—from consideration and the exclusion of people in regional, rural and remote locations, which has a specific

effect on LGBTI people living in those locations as well as in the general population, of which LGBTI people are a part. There is also the need for safeguards to prevent LGBTI people's suicide due to stigma, discrimination and social isolation, and I do have some of the statistics on that in Australia available to discuss. Also, there is the dual need to ensure the inclusion of LGBTI people's designated families—people that a person themselves considers family—without privilege or assumption that biological ties will be involved, and protection from unwanted influence of biological relatives, such as when someone who is biologically a relative is automatically treated as family without it being checked with the person themselves, particularly when that person may not wish the involvement of that biological relative and may not consider them family. The final issue is the need to address in a systematic and comprehensive way the existing gaps in LGBTI awareness, knowledge and skills in respite care, palliative care and other sectors that intersect with people who receive end of life care.

We hope that our involvement in this hearing will help the committee to ensure that any legislation resulting from this inquiry, no matter what the decision is regarding whether or not certain services will or will not be prohibited or permitted, will be responsible and inclusive. We hope the resultant legislation will protect both the autonomy of individuals who face very challenging existential choices and also the welfare of those individuals who may experience marginalisation and social exclusion. We thank you very much for providing us with the opportunity to address these nuanced points, even though we did not come out with a pro or con position on the legislation itself, and also to continue to promote the beneficial health and wellbeing outcomes that we seek for LGBTI people across the lifespan. Thank you very much.

CHAIR: Can you elaborate on the stats on suicide?

Dr Ansara: I have some information for you, although it is a bit nuanced because part of it is a critique of the suicide statistics themselves. The available evidence indicates that suicide rates are higher in LGBTI populations than among other Australians. Australian evidence found that 20 per cent of trans people—Couch et al, 2007—and 15.7 per cent of gay, lesbian and bi people—Pitts et al, 2006—reported suicidal ideation, which is higher than in the so-called general population—but, again, people are part of the general population so it is higher than in non-LGB respectively and non-trans-populations. Also, Australian research on LGBTI younger people does report higher suicide rates. Robinson et al 2014 found 41 per cent of LGBTI young people had thought about self-harm and suicide, 33 per cent had harmed themselves and 16 per cent had attempted suicide. This research also found that there were differences within LGBTI populations in suicidal ideation, so it could not be said that LGBTI people have a single rate, because these are different populations with different needs and life experiences. For example, one in four trans people reported suicidal thoughts in the past two weeks in one study, with almost twice as many people described by researchers as being assigned as male reporting a depressive episode than those who had been assigned as female. There was a difference. It was not always clear from reading how people themselves identified, so that is another issue in terms of the research. You see this often cited statistic about people being 14 times more likely to commit suicide, but that statistic comes from a report by Suicide Prevention Australia. It was a statement they made about the wide range of LGBTI suicide attempt rates that had been reported—some of them were from almost as long ago as 15 years. The point of that statistic was not to say that people are 14 times more likely; it was to say that a wide variety of rates have been reported, internationally as well as in Australia, and a lot of them are using small samples, they are not population-based, and there are issues with a lack of consistent population-based data on suicide statistics in Australia.

CHAIR: In relation to the bill, I was wondering whether there is any differentiation or division of rates of suicide between the general LGBTI community and those who might have a terminal illness.

Dr Ansara: I think we do. Again it is hard to know because of the lack of consistent reporting. One of the things that was mentioned in the submission by AFAO and NAPWHA was botched suicide attempts. There has been research evidence, as well as anecdotal evidence from organisations that provide services to people, that there are many people who experience life-limiting conditions and that suicide rates do increase as a result of that. With older people, from a generation when HIV was considered much more of a death sentence than it is today, this is concern. As you know, there are increased rates of HIV among older people—who tend to be more socially isolated—in quite a few populations. We do not really know how that plays out across populations.

One of the key things here is that social isolation is a key factor in determining how people handle conditions that are considered terminal. For example, I was speaking yesterday with one of the people who administers Qlife, a project administered by the alliance in collaboration with our partners across the states and territories to take what were the local counselling services—some of them were only gay and lesbian counselling services; some of them were more inclusive—and transform them into a national service that provides support and counselling to people. People do not have to be in crisis to access the service. There is a telephone line and there is also a chat based option. One of the interesting things was that, when I was talking to them about who was calling, I was told

that there is a population of older trans people who call and that these people are very isolated and do not have support from what you would consider family.

How this plays out is that, as people get older, they may get terminal illnesses. A lot of our populations do not have that social support that allows people to, for example, find other people to care for them or manage the emotional stresses, help them make decisions or even manage physically—in the sense of shopping for groceries and doing other activities of daily living. What can happen is that people can get very overwhelmed. I can say this just from my experience with people I have provided direct services to in previous roles—not through the alliance. What I saw in the community when I was doing outreach, directing a peer crisis intervention project, was that people were coming to us with many kinds of problems which I think other populations were not experiencing to the same extent.

CHAIR: I understand the point you are making. We have limited time, unfortunately, so I am trying to relate those statistics to the bill before us. But I will stop there and pass on to Senator Ketter.

Senator KETTER: Referring to your submission, would I be correct in saying that your organisation's neutrality on the issues flows from the alarming statistics about suicide rates amongst the LGBTI community?

Dr Ansara: I think it flows from the fact that we have members with many different experiences and views. It just was not possible for them to reach agreement.

I think the reason that I am saying that the suicide statistics, the social isolation and the historical marginalisation are relevant to this bill is that people are less likely to have others around to advocate for them. They may be in a situation where they are more likely to experience depression with suicide, so that is one thing the statistics do show in Australia. Suicide statistics in Australia, for non-LGBTI populations, show a certain percentage of people who have been diagnosed with psychotic disorders; whether or not we feel that is accurate is another story. The point is that they have those diagnoses, so they are having symptoms that are not necessarily about being miserable but there is something going on cognitively for them or they are having various kinds of mental issues; whereas for LGBTI populations it seems that depression is much more likely to have been a factor in the lead-up to people's suicide.

In relation to why that is relevant to this bill, I will give you an example of a concern: let us say there is a person who is very isolated and, as a result of that, is becoming more depressed, and they have a condition that although it may be considered terminal is something that they may be able to manage with the right psychosocial supports, but they are very isolated and they do not know anyone else like them. So this has a knock-on effect, it compounds the sense of desperation and the sense that life is not worth living. In some cases, that lack of social support is the intermediary buffer between a person saying, 'You know what, I want to end my life' or not. From what we heard from personal stories, and one of them was included in our submission, there were many cases where people said that encountering someone who did provide that support, or having connections with community resources of other people who could share a similar experience and who were welcoming towards them—especially when biological family members were not—actually made the difference between them wanting to live and wanting to die. I think that that is quite profound.

When I mention the suicide statistics and I mention the issue of social isolation, I want to be very clear that those things are directly related in many cases to whether or not people within LGBTI populations feel that life is worth living or would potentially choose to want to die. So I think that any legislation that addresses this really needs to address that concern and that relation between those particular variables. I hope that is a bit clearer. I think all of this is very relevant to this particular bill.

Senator KETTER: The exposure bill seeks to exclude somebody who is diagnosed with clinical depression, but I note that you still have a concern about the bill.

Dr Ansara: Absolutely.

Senator KETTER: It goes to the issue of lack of support for people. Is that the major concern?

Dr Ansara: I think another issue is that in our populations historically—and in some of the populations even currently—there is tremendous distrust of mental health professionals. I note particularly in the case of many people of trans-experience, gender diverse people as well as for people with intersex bodies people have experienced being 'pathologised' and being judged. A lot of people who seek to affirm their gender through medical means have had the experience of being told, 'No, you can't get what you want.' So there is a history of people having to tell a particular story to get services that they need and that story may or may not reflect what is actually going on. Given that history, it seems that in many cases it may not be easy to tell whether or not someone has clinical depression when they may not feel safe to disclose all of that information. There are a lot of

people who have difficulty finding a mental health professional who is understanding, respectful and supportive to them. I think it is that interface in the system between the different people involved that makes that potentially precarious for some people.

Senator KETTER: On the issue of palliative care, is knowledge about palliative care and the advances in palliative care and disseminating that information something that organisation has anything to do with?

Dr Ansara: We do have an ageing and aged care project, and we have had various kinds of contact with Palliative Care Australia. Just as increased information about and contact with community organisations such as LGBTI organisations can be very helpful, I think that information on improvements in palliative care is helpful. Particularly important to this population is information about the reception that they will receive in palliative care settings, about palliative care settings that are welcoming, inclusive and that understand their specific needs, as well as the fact they share the needs of many other people who are not in these populations. That is very important. One of the key issues is the kind of information that is necessary and is given to people before such a process would happen and whether it includes not only general information about palliative care, but also how it will affect this specific population or this person given their relationship history, their sexuality, their gender and their body. That was just one thing we identified as being really important as a safeguard in this process.

Senator KETTER: Doctor, are you familiar with any other jurisdictions around the world where euthanasia has been introduced?

Dr Ansara: I am familiar with the fact there are some regions where legislation of this kind has been introduced.

Senator KETTER: Are you familiar with the Dutch experience?

Dr Ansara: I have some knowledge but I would not call myself an expert on it.

Senator KETTER: Are you familiar with the fact that there seems to be a fairly significant increase over the past five or six years in the number of people choosing to access voluntary euthanasia?

Dr Ansara: Yes, I am aware that it has increased.

Senator KETTER: Are you familiar with the types of cases that are now emerging of people who are accessing euthanasia?

Dr Ansara: Yes, I am aware that it is a controversial issue, even in places where it has been allowed legally. There have been situations where people who had psychiatric issues were part of these euthanasia decisions, and in some cases they have shown that doctors did not meet the legal requirements. So one of the concerns would be how you determine informed consent. When you are talking about historically marginalised populations like LGBTI people—but it could apply equally to homeless people or people from CALD populations, or people with various kinds of mental health diagnoses—it might not be clinical depression. It might be other life-limiting conditions. Some of those could be psychiatric, some could be physical. It is very tricky in that there is no universal system that can protect people from an inappropriate situation happening. I would be more concerned with people who at times, historically, have been considered 'throwaway' people or have been marginalised or discriminated against in a medical context. That is why LGBTI populations are one of those I would be concerned about. There would be other populations too, but that would be one of them.

Senator DI NATALE: Going to some of the recommendations in your submission, do you agree that a psychiatrist needs to be involved through the assessment process?

Dr Ansara: One of the concerns that we have heard from many people in LGBTI populations is in regard to the profession of psychiatry. The official manuals used in psychiatry are still pathologising, and many of our constituents consider them discriminatory towards them, particularly when you talk about people with intersex bodies and people of trans or gender diverse experience.

Senator DI NATALE: But the psychiatrist is really making an assessment about whether somebody is clinically depressed and, secondly, about whether that depression is affecting their ability to make a clear judgement.

Dr Ansara: Right. As you may know, clinically accurate information is elicited from people based partly on the rapport that is established. The issue there is that a lot of people do not feel comfortable with psychiatrists in our population because of past experiences. In other words, they may be in an encounter and may not feel comfortable disclosing enough information so that an accurate clinical assessment could be made. So I think that broadening it to, for example, clinical psychologists may be useful. Broadening it beyond just psychiatrists I think may be useful. Obviously, there is specific training, I would say, in this area that would be needed by any medical practitioner or mental health practitioner who is involved in making these assessments. Just because someone is a

psychiatrist, regardless of their training, specific training in this area is needed, particularly I would say specific training in how this would affect certain vulnerable or historically homogenised populations, which could include these people.

Senator DI NATALE: Would it be fair to say that there would be perhaps a small number of psychiatrists who have expertise with the LOBITO community and have the trust of members of the LGBTI community, maybe because of their specific expertise in the area, and maybe allowing a provision for some sort of outreach service that involves those people in the assessment?

Dr Ansara: I would say there is a difference between people who have expertise as psychiatrists in the sense that they work with certain populations and people who community members would necessarily feel safe with. And yes there are some of those people but there are very few of them. Of the people who work with people, not all of those people have community trust. So I think that definitely having a provision that would allow a non-psychiatrist who has the appropriate training to be involved there would be really helpful because, depending on what the demand is, it might be very problematic if people have to do it, particularly if they are in a vulnerable place anyway and experiencing distress. It would have to do with a psychiatrist versus another kind of reputable professional who can make a determination of clinical depression or other sorts of diagnoses. I would say that opening its a bit wider would make it more inclusive.

Senator DI NATALE: But you would still say that it that it is important to have a mental health professional involved in the assessment process?

Dr Ansara: I would say that it is important not only to have a mental health professional involved in the process but a mental health professional who has specific training in this particular area, which many do not including psychiatrists, and specifically that they are trained in recognising and identifying people who are from vulnerable populations which we know have higher rates of suicide partly due to stigma and vulnerabilities and that those people make a very integral part of the process to connect people or to offer them services and access to various community organisations. I think that is a key step and is something which I think might be missed because even if you are just making a determination of whether or not someone is clinically depressed, you can make that evaluation and you might have experience with the population but that is not the same as saying, 'I'm going to tell you about community resources which might be available to you if you are a lesbian, an older lesbian and you are alone without social support in a rural area. Here are the services that could help you. Here are the places you could go. Here's access to that information.' The connection with community and with peer support is crucial for people and does make the difference in many cases between whether or not someone chooses to live or chooses to die.

Senator DI NATALE: I agree with that but we need to be clear. We are talking about people who have terminal illness, not somebody—this is specifically for people with a terminal illness who are experiencing intolerable suffering, yes?

Dr Ansara: Right. I guess what I am saying is that a lesbian who has been diagnosed with terminal cancer and told, 'This condition is eventually going to cause your DS, sooner rather than later,' in multiple cases where people had given me information for this inquiry they told me that, with their friends, their partners, their family members, access to social support made a difference to them.

In other words, I get the fact that they are suffering but, given the tremendous suffering that it also leads to among their loved ones and in communities, it is really important to make sure that people have the opportunity to know about supports available to them. It is quite surprising to imagine that many people do not know about the support that is available to them.

I am saying that a big part of managing the suffering and determining whether or not it is bearable, and whether it is something that requires someone to end their lives versus continuing to manage in some way, depends to a large extent, for many people, on the extent to which they feel socially excluded.

Senator DI NATALE: In your submission you also mentioned that the bill does not address people's choice of place in which proposed medical services will occur. I am not sure what you mean by that. I think you are implying that people oppose dying in a hospital environment. It could be applied in that way. Ultimately it would be up to the choice of the individual. The bill is drafted in a way that allows the person to make the decision. I am not sure what aspect of the bill you think imposes the choice of place in which the medical services would occur.

Dr Ansara: I think that was feedback from one of my colleagues. The feedback was based on the need to make sure that it was more explicitly stated that people should have access to a location of their choice. I think that to that particular person it was not clear that that was the case. So it might just be a matter of clarifying that.

Senator DI NATALE: Yes, we can go back and have a look at that.

CHAIR: That does it. Thank you very much Dr Ansara. We very much appreciate your submission and your time today.

Before I call the next witness, I notice that we have a group of the general public in here, comprising a number of young people who may find it a little bit strange that we are here, more or less talking to ourselves, or to the stratosphere or something. This is a committee inquiring into a bill that has been proposed to parliament called the Medical Services (Dying with Dignity) Exposure Draft Bill. Some people refer to that as euthanasia. The committee is looking into the provisions of that bill. Because a lot of the witnesses live in other parts of Australia and cannot get to Canberra for our hearing we have them on a teleconference. Unfortunately, our last witness and our next two witnesses are attending via teleconference.

Normally, the witnesses come and sit at the table opposite us, and we can question them here. Lest you think it is a bit strange that we are sitting here talking to ourselves, that is the reason. Welcome, in any case.

BONYTHON, Dr Wendy, Private capacity

ARNOLD, Mr Bruce, Private capacity

[14:23]

Evidence was taken via teleconference—

CHAIR: Welcome to these proceedings. As you are aware, this is the Legal and Constitutional Affairs Legislation Committee and we are looking at Senator Di Natale's Medical Services (Dying with Dignity) Exposure Draft Bill 2014. Thank you very much for joining us and for sharing with us some of your very valuable time to contribute to the committee's deliberations into the bill. We have your submission, which we have numbered 87. Thank you for that. You would be aware that this is a parliamentary inquiry and the hearing is open to the public and attracts parliamentary privilege. If there is anything that you want to say in private, you can raise it with the committee. If you want to add to or amend your written submission, you can do that now. Would you like to comment on the capacity in which you appear?

Dr Bonython: The submission is co-authored by my colleague Assistant Professor Bruce Arnold and me. We make our submission as individuals from an academic perspective. We are not speaking on behalf of the University of Canberra.

CHAIR: I now invite you to make a brief opening statement and then we will ask some questions.

Dr Bonython: My colleague and I commend the committee for conducting this inquiry. Euthanasia is a matter of fundamental importance: the ultimate issue of life and death. In that context we believe it is critically important that the community as a whole be given the opportunity to participate in a national conversation about euthanasia laws. Inquiries such as this one do much to facilitate that discussion. For the record, neither of us is affiliated with either pro- or anti-euthanasia groups. Our comments today, and our submission, critique the draft bill as a matter of law rather than engaging with the more philosophical aspects of the practice of euthanasia itself.

We have a number of concerns about the bill which are outlined in detail in our submission. These include the source of the power to legislate on the issue; the lack of coherence in terminology; the inadequacy of safeguards; and the arbitrariness of the immunities concerned. At least some of the submissions received by the committee argue in favour of the bill, citing existing practices which currently—and, they argue, wrongly—occur outside the law. We would argue that passing inappropriate or underdeveloped legislation will only compound those problems by creating a theoretically lawful but practically ungovernable framework. We suggest that a better approach might be to engage the community and develop a more robust draft bill—if indeed the community indicates that that is what is required.

Senator DI NATALE: Thank you very much for your presentation. There are three areas in your submission that I could talk to. I will not talk to the first one—that is, the question of the social context of the proposed bill. I suspect there will be different views about the best way of getting this reform through, so I will leave that alone. I think that is a subjective judgement. Regarding the constitutional validity of the bill, we have received conflicting advice on that issue and it is probably something that would end up being settled in the High Court. What I am most interested in and very grateful for is your detailed response to the exposure draft. I reiterate that this is an exposure draft, which means that we are very open to any suggestions in terms of ensuring that the bill has rigour. On that point, let's go to some of your specific concerns. You suggest that some of the language is confusing and you make a number of comments on some of that language. So perhaps we should go directly to the terminology—'euthanasia', 'assisted suicide', 'mercy killing' et cetera. Do you have a view about what the appropriate language is that should be used when we are discussing this bill?

Dr Bonython: It does not so much matter which terminology you use, so long as it is used consistently and it is clearly defined. One of the things that you find throughout the literature and also when talking to people about their views is that often you might have a group of people using the same terminology but they actually mean quite different things by that. It very much extends to some of the discussion around capacity, soundness of mind and those sorts of issues as well. It is more a case of picking a particular set of language that you have a clear definition for and sticking with it so that at least everybody knows that they talking about the same thing.

Part of the problem is there is a lot of media reportage around it. People are using different terms like 'mercy killing', 'voluntary euthanasia', 'active euthanasia', 'passive euthanasia' and 'withdrawal of life support', and there seems to be a great deal of confusion amongst public discourse about what the actual topic of discussion is. I think it is really important that a bill dealing with this has some really clearly defined parameters and scope. Otherwise it is going to lead to uncertainty and ambiguity, which is going to make it very difficult to implement in practice.

Senator DI NATALE: We have no control over the way the media report the issue, but we do have some control over how we describe it in the bill. Do you have a preferred term?

Dr Bonython: I do not have a particular preference for a term, as long as it is clearly defined and consistent throughout the bill.

Senator DI NATALE: Okay. Let me go to the question of terminal illness. Do you believe that requires definition?

Dr Bonython: Yes, absolutely.

Senator DI NATALE: Do you have any suggestions on that front?

Dr Bonython: I think you need to think very carefully about the scope of operation. If you are talking about somebody with mental illness who is prone to suicidal ideation, for example, from their perspective they may view that their condition is non-responsive and therefore terminal. If you want to limit it to people who say, 'This is a terminal illness which will kill me within a set time frame,' as opposed to, 'This is a chronic illness which I am going to die with rather than of,' this is something that I think needs to be clearly articulated.

I would be more concerned about terminology being used without it necessarily having been thought through and defined. What do you want the bill to do? When do you want these services to become available? Are they going to be limited to people who have a clear prognosis that the cancer is not going to go away and who are talking about life expectancy in terms of weeks and months, or are you looking at extending it to people who may have something ultimately like a genetic predisposition to a type of cancer but do not have any actual transition to the disease state yet? I think it is important that the terminology around what a terminal disease is for the purposes of this bill be really, really clear.

Senator DI NATALE: So, at the moment, that really leaves the discretion in the hands of the medical community, and you believe that that is not appropriate?

Dr Bonython: I think it is problematic because ultimately this is going to end up before the court, and we are seeing from the reporting coming out of the medical community that there is a great deal of difference of opinion over what euthanasia is, when it is acceptable and when it is not acceptable. You do not have to go too far beyond the published medical literature in Australia to see that there are some practitioners who have some very grave concerns about the direction that euthanasia has taken in other countries where it has been implemented. Events in Australia have indicated that there is disagreement within the medical community about when it is appropriate to offer euthanasia services.

Senator DI NATALE: You also mentioned the concept of capacity. Again, I think the bill is drafted in a way that it refers to that in different ways.

Dr Bonython: Yes.

Senator DI NATALE: That has been noted. You also say that there is a notion of medical capacity versus legal capacity. Do you think that needs to be further defined in the legislation?

Dr Bonython: Capacity is something of a vexed issue in every context it arises in Australian law at the moment. There is a difference between medical capacity and legal capacity. One of the things we know about capacity is that it is a fluctuating, context-dependent and often time-sensitive concept. I think it is worth being aware that if you are talking about capacity you need to be focusing on that specific question. I mention further on the emphasis on medicalisation of the model. One of those tests around capacity is making sure that the person has a full understanding by explaining it to someone who is not a medical member. That is one of the safeguards.

Moving on from the issues around capacity—and I think they are very similar in this context to other situations, such as guardianship, power of attorney and other sorts of specific medical procedures—the bill in its current form further compounds some of that confusion because it does not just talk about 'competence' and 'capacity', which it seems to use interchangeably; it also has references to things such as 'soundness of mind' and a few other terms that are not so much in favour in legislative or court drafting because of their uncertainty. They are very traditional rather than clinical or social terms.

Senator DI NATALE: Just explain that to me. When you talk about capacity in a legal sense, is there a standard definition?

Dr Bonython: There is not. The test that is most commonly used is that one identified in *Banks v Goodfellow*. That arose in the context of testamentary capacity—so the facility of someone to make a valid will leaving their estate. The test they had was that the testator needed to understand the nature of the act and its effect, understand the extent of the property of which they were disposing and be able to comprehend and appreciate the claims to which they sought to give effect.

Moving on a little bit further from that, we usually see requirements for capacity including elements such as the person understanding what it is they are deciding to do and being fully aware of the consequences of that decision and the potential ramifications or risks associated with it. They need to do more than just say, 'Yes, I agree.' They actually need to have a full understanding of what is going on in order to demonstrate that it is a decision being made by someone with capacity who is exercising that capacity in consenting to that decision.

Senator DI NATALE: You also talk about the question of immunity from legal proceedings. How would you improve that?

Dr Bonython: One of the problems I have with the immunity provision is that, coming from my perspective, I look at it and think, 'It protects a doctor, but it does not extend to the people who are facilitating the act of that doctor.' Doctors do not generally have a stash of the relevant sorts of pharmaceuticals with them. They have to get it from pharmacists. Do we end up with a situation where the doctor sources drugs from a range of pharmacists so that each one of them is supplying a less-than-lethal dose? But, also, what are the complications and implications if that doctor is working for a bigger entity, such as a state health department? Does that immunity extend to their employer? Under the principles of vicarious liability, they would be liable and negligent in the event of a lawsuit potentially brought by a relative on the basis of wrongful death.

Senator DI NATALE: So the immunity provision should be extended to protect both the employer and also any other associated entities that have been involved in the procurement, distribution and administration of the drug—would that address your concerns?

Dr Bonython: If that is the model you choose to adopt then, yes, there needs to be a broader immunity. Otherwise, you are privileging the practitioner but ignoring the fact that they are not operating in a vacuum. You also still have that complicating context that treatment of terminally ill patients is provided in multidisciplinary teams. How does this immunity sit against mandatory reporting laws for other practitioners and professionals engaged in those teams? What sort of obligations are they under? If a doctor has immunity, does the nurse who does not report the activity to their professional board face sanction? How do you make that immunity apply fairly and equitably across the board?

Senator DI NATALE: What would you say about the consent provisions? What are your concerns about that?

Dr Bonython: My main concern about the consent provision is that it is overly medicalised. We have a whole body of case law that illustrates that doctors do not necessarily have a fail-safe approach to gaining informed consent. We have a lot of case law on it and we know that there are standards. It is not a perfect system. I think one of the better ways of ensuring that people really do understand the nature of what it is they are deciding to do, and what the implications are, is to bring in an external person who is not a clinician; who is not associated with that very medical model of care, and getting them to ask: 'What do you understand by this? What do you think the consequences or the implications of this are?' Actually getting people to actively express their understanding, rather than simply allowing the potential for it to be reduced to a signature on a form or a 'Do you understand yes/no' kind of closed question, which is not a particularly effective mechanism for validating consent.

Senator DI NATALE: Are there any examples of where that occurs? I am just trying to think that one through. Who would be the body that would be brought in?

Dr Bonython: There are a whole range of options that may be relevant. One of the models you might look at is something like the context of organ donation. There are quite a lot of systems around the world where, once you have a family who is in the position of considering organ donation, they actually talk to somebody who is independent of both the organ donation team and the hospital, and all of those sorts of people. They are given an opportunity to work through and discuss some of those things. I am not particularly certain who it might be that would be suitable. It could be a lawyer. It could be a social worker. It could be a counsellor. In some contexts, it may even be their religious person or a chaplain. Someone of that nature is an appropriate person. There needs to be somebody not affiliated with the hospital and not wearing a white coat, and not in that position of doctor/patient imbalance—just acting as a sounding board, and validating that the person who is requesting these services is not subject to undue influence and considering things that should not be having a role in their decision making. They should not be associated with the hospital—there is no question about bed availability or resourcing, or anything of that nature.

Senator DI NATALE: And when you talk about the medicalised model—are they the things specifically you are referring to or are there other areas that you are concerned about?

Dr Bonython: I am not sure I understand what—

Senator DI NATALE: You referred to consenting information in your submission; then you express concerns about the 'excessively medicalised model' proposed in the bill. Does that relate specifically to those two criticisms you have talked about: the immunity provisions; the informed consent proposal where you have really just got the doctor involved? Or do you have any other concerns around what you refer to as the 'excessively medicalised model'?

Dr Bonython: My main concern is that lack of involvement in the whole process by anyone who is not a clinician. I think that there needs to be a broader based support framework implemented and there needs to be engagement with some people who are not clinicians. I think that is as much about protection of the rights of the person, as well as—we have a whole body of evidence that says doctors are great at being doctors, but sometimes they are not necessarily across getting valid and fully informed consent. Having that external safeguard, or check, in place is a way of also recognising that death, like life, is more than just a collection of symptoms treatable by somebody in a white coat. A person may die of a disease, but that does not mean that the disease is all they are. It recognises that there are more aspects to human life than just a collection of symptoms, which may in this case be terminal.

Senator DI NATALE: Finally, I just want to go back to that issue of decision-making capacity. You reflect what, I think, one of the earlier witnesses has suggested—that really treatable, clinical depression is not the central issue here; it is really the issue of capacity.

Dr Bonython: Yes.

Senator DI NATALE: Then you go on to say that perhaps we should deal with it through an option of last resort.

Dr Bonython: Yes.

Senator DI NATALE: Can you just explain how that works—how that might work?

Dr Bonython: One of the problems that I have with the bill is that there seems to be an underlying assumption that a person who has mental illness automatically lacks capacity—which we know is not true. There are plenty of people with mental illness in the community and, indeed, people with severe episodic mental illness who, for much of their lives, have perfectly valid legal capacity and are capable of making their own decisions. That in and of itself should not be the litmus test by which you say, 'These services are available to you but not to you.'

By talking about it as an option of last resort, I have suggested that it would make sense to look at what some of the options available are and if there are other things that could be considered. Let us say that we have somebody who is really struggling today. Have we explored all of the options of medication and adjustment of pain relief and all of those sorts of things? Is there anything else that could be considered? This arises in the context of a lot of the discussion about the dignity of the person who is dying. Maybe we need to look at some of those issues associated with dignity as well rather than just pain and disease management, and look at treating them more holistically rather than just, 'Well, we don't think this drug is going to cure you, therefore we are down to clinical last resorts.'

Senator DI NATALE: Could I explore that. Isn't the last resort clause you suggest—'reasonably likely to relieve the pain, suffering or indignity intolerable to the patient of being attempted or considered'—a very broad definition? We heard earlier, for example, from a palliative care physician who was opposed to any form of assisted dying who would argue that it would be reasonable to attempt to ensure that somebody is within a palliative care environment for a specified period of time before you attempt to go down this path. Whereas somebody with potentially weeks to live might argue that they would prefer not to have to do that but to perhaps end their life at home.

Dr Bonython: Yes. I think it depends a lot on whose version of 'reasonable' you are talking about. The bill emphasises, 'Is this something that the patient can live with', and that is certainly what the emphasis should be on: is it something that the patient thinks would be a reasonable attempt?

It also says that it should be considered—not necessarily that it has to have been attempted. So, in the situation you illustrated, if you had a person who passionately wanted to die at home, who had no inclination to go to a palliative care facility when the option was presented to them, who has had all of the relevant information provided to them, has considered it and decided it is something that they are not prepared to do, then they have given it reasonable consideration. They have thought about it. They have weighed up the pros and cons and decided against it. That is fine. That is demonstrable consideration of what might be a reasonable option.

Senator DI NATALE: How would you demonstrate that someone has considered all of the options?

Dr Bonython: You provide them with the information and then you engage in a conversation with them and say, 'Okay, this is what sort of things can happen in a palliative care facility. What do you understand by it? Do you have any concerns about it?' It must be actually engaging in a meaningful conversation with them rather than doing a very superficial passing of an information brochure and saying, 'Any questions? No? Good. Let's move on.'

Senator DI NATALE: I agree with you, I think that is important. But how do you ensure in law that that occurs?

Dr Bonython: From my perspective, this is where I think it is valid to have that external third party coming in and move away from the medicalised model. We see a lot of that happening anyway, because—certainly in a lot of the public hospital sectors—we have people who work in this area. We have palliative care social workers. This is the kind of conversation that they are having on a regular basis. We have people out there who have the skill sets that enable them to talk to people who have had diagnoses of terminal illness, and they can present them with their options. They can support people in working through those options, picking out what they are comfortable with and discarding options that may not work for them, but it is a conversation between equals, not wearing white coats and not necessarily around that whole medicalised model of consideration.

Senator DI NATALE: Thank you very much. That has been most helpful.

Senator KETTER: I will first quote from the covering letter to your submission. Quite a confronting statement is made. You say:

... the Bill, if passed, will provide a basis for legalized euthanasia of 'the inconvenient' – people with impaired capacity, long-term severe disability, or an inability to pay for health care – in the interests of economic rationalism.

Dr Bonython: Actually, it also says that it would 'contribute to uncertainty, and add to the fears within some sectors of the community'.

Senator KETTER: Yes. Are you saying that those fears would not necessarily be well founded?

Dr Bonython: I am saying that I do not necessarily believe in some of the conspiracy theories running around at the moment. Nonetheless, I think there could be ways in which the bill will be interpreted by some sectors of the community. It is the classic slippery-slope argument: we passed this, now we can start looking at ways of expanding it. We have seen this through some of the reporting that has come out of other jurisdictions as well. Belgium in particular is an example of where what was originally a fairly narrowly defined scope has broadened, and incrementally, case-by-case, the boundaries have become a bit greyer. It is a comment about fears within sectors of the community rather than my beliefs on the actual legal meaning of the bill.

Mr Arnold: This is one reason we think it is really important that there should be a broad, fairly deep public discussion about this.

Senator KETTER: But those fears based on the Belgian experience would be reasonably well founded, wouldn't they?

Dr Bonython: Sorry?

Senator KETTER: The fears that you have talked about amongst the general community: when looking at the Belgian precedent, there would be some basis for those fears, I put it to you.

Dr Bonython: Yes, I think in some instances they may well be well founded. I am not terribly persuaded by some of the campaigns I have seen along the lines of states encouraging people to adopt euthanasia. I would find that an absolutely horrifying type of option. But I think there are circumstances in which in some jurisdictions people have perhaps opted for euthanasia before they have exhausted all other sorts of resorts in a reasonable fashion.

Senator KETTER: I would like to come back to that, but I would like to take you to your comments about the level of the public debate about euthanasia and the fact that you do not believe it is sufficiently mature. You mentioned the fact that there is confusion in respect of the terminology that is being used. Are we ever going to get to a situation where the debate would get to clarifying terminology in the precise fashion you have referred to in your submission? That is a fairly sophisticated level. And looking at the current media capacity to ventilate this issue, one would wonder whether that is ever going to be possible.

Dr Bonython: I think as far as public discourse goes you are probably not ever going to come up with an agreed set of terminology. I do, however, think that in the context of legislative drafting it is important that it is very clear what exactly it is that the parliament means by a particular term when they include it in a draft bill. I also think that if you look at some of the studies and surveys and even the differing opinions that have been put forward on this issue, it is clear that we are sort of getting buried in avalanches of statistics, many of which are

being collected and reported by people with a particular perspective. There is a lot of confusion amongst people about what this means, what the limitations of it are. And I think until we have a really clear understanding of what it is we are talking about here, it is problematic to pass legislation on it in that particular way. It comes back to that earlier comment about there being fears within the community: 'When I get old and run out of money the state's going to force me to do this.' We should not underestimate the capacity of the public to engage with these issues. I think this is one of those ones where it is important to make sure that people are being heard and that it is not a discussion that is occupied entirely by people who are very much one way or the other. We need to engage with the people who are undecided and make sure that, if they continue to be undecided or ambivalent about it, at least they are doing so from a position of information rather than just: 'Well, there is all this polarised rhetoric and it doesn't really bother me.'

Senator KETTER: Okay. I just want to continue on from your previous discussion with respect to the option of last resort. You have talked about the fact that:

A better drafting approach would be to incorporate an 'option of last resort' clause as a criterion for provision of the services, such that all options 'reasonably likely to relieve the pain, suffering, or indignity intolerable to the patient have been attempted or considered'.

And you talk about the fact that the 'inclusion of "reasonable" allows futile treatments to be disregarded' and then you say:

... the requirement that alternatives be considered, if not followed, means that the patient is not bound to try a therapy they may find repugnant, but does require that they be presented with a full suite of options ...

How can we ever be satisfied that a patient is going to be presented with the full suite of options?

Dr Bonython: There is fairly well-established literature about what sorts of things we would expect a competent palliative care practitioner to be discussing with their patient. And that comes back to the sorts of tests we see in medical negligence law. What would the reasonable practitioner in this position do? What sort of information is the patient reasonably likely to want to know about? You would not necessarily want to create an environment where a doctor had to outline every very, very preliminary drug trial happening in South America and say: 'Okay, there is no data in on it yet, but it's a last chance.' I would hate to see it being interpreted to validate some of the, perhaps, less credible stem cell therapy trials and those sorts of things that we have seen.

However, that being said, there is a fairly clear body of knowledge—and that is encapsulated in things like professional standards, professional guidelines and all of those sorts of things—which govern what sort of treatment credible, registered practitioners are providing. It gives us a sense of what the reasonable practitioner is discussing with their patients, in these circumstances. We have already got a lot of that information there. Ensuring it would simply be a matter of saying: 'Now that I've provided you with this information, can you explain to me what you understand by that? What information do you think works for you; what options don't you want to try?' And ensuring that they are actually understanding that information, rather than simply receiving it.

Senator KETTER: Just along those lines, we have already heard today from previous witnesses who talked about the fact that even some of the medical profession are not aware of the advances that have been made in palliative care. There are some issues in relation to assuming that the medical profession is in a position to provide the information that would lead to informed consent. What is your reaction to that?

Dr Bonython: I suggest that that is probably more significantly an issue related to professionalism of medicine, rather than euthanasia specifically. You hear the same sorts of comments in a whole range of contexts. There is a lot of information for practitioners to remain across, but there is also an expectation that if practitioners are not able to give accurate, up-to-date informed advice they will refer patients on to other practitioners who are.

I would be horrified if there were palliative care practitioners who were not up to date with current knowledge in their fields, for example. If you had a practitioner who did not have that up-to-date knowledge, then, as a matter of professional conduct, you would be expecting them to refer the patient on to somebody who did have that information at their disposal. But that is not different from any other area of medicine.

Senator KETTER: Finally, on the issue of constitutionality, you suggest a number of different ways that could be cured.

Dr Bonython: I do not know that I came up with—

Senator KETTER: Perhaps that is not the right word. 'The likelihood of successful challenge being mitigated'—is that a better terminology?

Dr Bonython: I think I suggested some problems with it. I do not know that I necessarily came up with any cures for it, particularly. Certainly one of the issues that we had is that difference in terminology between pharmaceutical benefits and medical services in section 51(xxiiiA) and the potential for the pharmaceutical model

proposed to be interpreted differently by the High Court than, say, a more medical model of service provision. I do not know that I came up with any particularly good solutions for working around that difficulty, but certainly I do think there is the potential there for the courts to say, 'Well, they've used different terminology. Clearly these two things operate within a different scope.'

Senator KETTER: Would it be fair to say that, however the bill is framed in terms of the constitutional basis, it is likely that there will be a challenge to it?

Dr Bonython: I would be very surprised if there was not. Health has traditionally been somewhat of a hot potato. The states are fairly territorial of it. Certainly I know that the territories in particular have had longstanding disquiet, particularly with the intervention of the Commonwealth in their euthanasia laws in the past. I think it would be highly likely that one or more of the states would seek to challenge it on the basis of constitutionality, simply because the argument would be made that, if you are starting to look at this particular area of health provision, what next? How long before we actually see scope creep right the way through?

CHAIR: Thank you, Dr Bonython and Mr Arnold. We very much appreciate your contribution to the debate and some of your very valuable time this afternoon. Thank you very much.

For those who may be following this, we had hoped to have a Skype discussion with a group called DIGNITAS from Switzerland, but unfortunately, because of committee members' airline schedules and difficulties in changing the time, we will hopefully have DIGNITAS appear at another hearing of the committee.

SHELTON, Mr Lyle, Managing Director, Australian Christian Lobby

SIMON, Mr Daniel, Research Officer, Australian Christian Lobby

[15:03]

CHAIR: I welcome the Australian Christian Lobby. Thank you very much for making your time available to us today. I particularly welcome Mr Daniel Simon and Mr Lyle Shelton. You may be aware that, as this is a committee of parliament, parliamentary privilege applies. If there is anything you want to say to us of a private nature, you should raise that with the committee and we may be able to go in camera. We have received your submission, which is submission No. 48. Thank you very much for that. If you want to make any alterations or additions to your submission, you could do that now. Otherwise, if you would not mind, you can give us a short opening address and then we will ask you some questions.

Mr Shelton: Thank you very much for the opportunity to appear in person here today. Since 2008, there have been 10 failed attempts to introduce euthanasia laws at state, territory or Commonwealth level. Many, if not most, of these attempts have been brought on by the Greens, a political party which nominates euthanasia and changing the definition of marriage as top political priorities. This issue has consumed hundreds of hours of parliamentary time. Now, I am not saying that issues cannot be brought up multiple times—persistence is certainly a virtue in politics—but I think questions now need to be asked about the Greens parliamentary tactics and their strategy of what seems to be trying to bring about legislation by fatigue.

In many of the 10 failed legislative attempts, parliamentary inquiries have been held and community and professional organisations have gone to the trouble of preparing detailed submissions and giving oral evidence. Parliamentarians upon, examining the evidence, have not been convinced. This is why parliamentary inquiries do not generally recommend legislating for euthanasia and why the votes in parliaments inevitably fail. I concede that opinion polls asking people if someone who is terminally ill and in intolerable pain should they be allowed to choose to have a doctor to end their life have gained some support. Certainly there are polls that show there is majority support and I acknowledge that. That is a proposition though that attracts popular support, but we must ask are the assumptions underpinning this which are commonly put in these propositions correct?

Those representing the public in our nation's parliaments have had the chance to dig deeper than a simple proposition put in an opinion poll and to examine the claims of the euthanasia lobby. Some of these are, and I am sure you have heard many of these today already, whether or not vulnerable people can be safeguarded from a new cultural pressure to, 'do the right thing and die'; whether or not people can be safeguarded from abuse; and whether a dignified death is possible without euthanasia laws. Former Prime Minister Julia Gillard got it right when she said:

I am not satisfied that euthanasia legislation can be enacted to make it safe and workable.

She went on to say that euthanasia would:

... open the door to exploitation and perhaps callousness towards people in the end stage of life.

Let us have a look at the experience in the tiny handful of jurisdictions that have legalised euthanasia. In Belgium, one study has found that nearly 32 per cent of euthanasia deaths had occurred without explicit request or consent. Another study found that only 52.8 per cent of euthanasia deaths were reported to authorities. The study said it is uncertain whether those cases that are not reported are dealt with as carefully as those that are. Another found that 12 per cent of euthanasia deaths were administered by nurses, despite the law prohibiting this. In the Netherlands, one study found 23 per cent of euthanasia deaths are still not reported after eight years of legal euthanasia. The same report found that ending life without an explicit request has decreased but not significantly. A survey of GPs in 2011 found that nearly half had felt pressured by patients, or their relatives, to use euthanasia. Twenty per cent of GPs said they were willing to euthanase a patient who is merely tired of life, even though the law requires unbearable pain as a condition of euthanasia. Belgium has recently passed laws allowing for euthanasia for terminally ill children of any age. Despite Belgium law requiring unbearable pain as a condition for euthanasia, twins Marc and Eddy Verbessem were euthanased after being told they would go blind. The Netherlands currently allows euthanasia for children under 12. Paediatricians in the Netherlands are pushing to allow euthanasia for children of any age. And I could go on.

There has been some recent cases of note reported in the international media which I think are worth bringing to the committee's attention. I have already mentioned the twins in Belgium—after discovering they would both go blind, they sought euthanasia. It took them two years to find a doctor willing to perform euthanasia, and they were euthanased at the age of 45. François, 89, and Anne, 86, are a Belgian couple who plan to be euthanased, I believe, next year. The couple planned it with their children, who say they would not be able to care for them if one of them died. They were also concerned that a good retirement home would be too expensive. They are not

terminally ill. A Belgian woman requested euthanasia because she was depressed had her request approved in 2012. Her son, Tom Mortier, was not advised of the decision until the day after his mother's death. A Belgium woman who became depressed after a botched sex change left her 'a monster' was euthanased in 2013. He was euthanased on the grounds of unbearable psychological suffering, despite not being terminally ill. Frank Van Den Bleeken, a Belgian murderer and rapist serving a life sentence, has been allowed to have euthanasia after arguing that he could not overcome his violent sexual impulses and so had no prospect of release. In the Netherlands, a doctor euthanased a woman in her eighties who had suffered a stroke—because she did not want to live in a nursing home. The woman had indicated in writing her desire not to live in a nursing home 20 years before her stroke and repeated this verbally 18 months prior. She was unable to communicate properly after her stroke.

Common factors in all of these cases are an absence of terminal illness and an absence of intolerable pain. If the safeguards we hear about are not working in those other jurisdictions, what makes anyone here think that we can achieve a world first in public policy with euthanasia? It is clear that the so-called safeguards are quite easily circumvented. Before there is any rush to legislate, parliamentarians must address the questions around safety and abuse of the law which arise from examples such as those I have just mentioned. We know that some of the deaths from euthanasia in the Northern Territory in 1996, when it was briefly legal there, were of people who were not terminally ill. We know that the law was breached. This was admitted by the administering doctor who told the Tasmanian parliamentary inquiry in 2009 that indeed there had been a breach of the law but that it was a breach motivated by compassion.

In his matters of public interest speech on June 25, Senator Di Natale, who is here with us today, said:

Given the choice that we have when it comes to dying, how many of you would choose to end your lives in a sterile hospital room, in unbearable pain, drugged into a semiconscious state, poked full of holes and tubes and lying there drowning in your own secretions and gasping for air when the alternative may be a peaceful death at home, with your family ...

This is a very confronting and heart-wrenching scenario, but I am not sure this is the correct way to be framing the alternatives. When I read Senator Di Natale's speech in preparation for this afternoon, I contacted a friend who is a senior lecturer in palliative care at the University of Queensland, Dr David Van Gend. He is a submitter to this inquiry. I do not have the submission number with me, but I certainly commend his submission to you. He emailed me today to say:

Many thousands of patients with distressing symptoms are managed well by qualified doctors every day. Phrases like 'drowning in their own secretions' are not helpful. If the patient is in such distress, that is more reflective of incompetence on the part of some doctors and the solution is better training of doctors in palliative care, not taking the patient's life.

Difficult respiratory symptoms can be addressed by a range of medications to dry up the secretions—

I will not name them because I cannot pronounce them—

and a range of medications to reduce anxiety associated with difficult breathing are also available, as is input from physiotherapists and expert nursing care.

In conclusion, I acknowledge that this is an emotive issue but I think we have to be careful not to allow the emotion to cloud logic in making public policy which suits everyone, including and especially the most vulnerable. Thank you very much.

CHAIR: Mr Simon, you do not want to add to that at this stage?

Mr Simon: I only had a couple of remarks to add. We mentioned in our submission what we might call 'a culture of death'. I was not suggesting that there will be widespread practice of doctors killing people against their will, but we do think there is a much more subtle and dangerous effect that would come from legalising euthanasia—and that is changing the fundamental relationship between doctors and patients, that relationship of trust that doctors are there to preserve life. We also refer to the subtle societal pressures that would come from saying that euthanasia is a preferable option. Even if you are saying that is only in some cases, it is effectively saying that pain and suffering are incompatible with dignity.

We talk about 'dying with dignity', but we submit that euthanasia undermines the dignity of human beings by attempting to make value judgements about the quality of life or standard of living of other people. We also talk about choice. That is one of the main things we talk about in arguing why euthanasia should be allowed for some people. But we submit that choice in many cases will be an illusion, because even though there may well be and are some people who do genuinely want to chose euthanasia, if we legitimise it and normalise it by legalising it, then we are saying that euthanasia really is an option that should be available to anyone.

Lyle alluded to cultural pressures. I think in the case Lyle mentioned of Francios and Anne in Belgium, they know that their children do not think they can look after them if one of them dies. It is cases like this, where, even in cases where elderly people may have very loving and supportive families, they know they are a burden on

them. They know that they might live for several more years. And they may just think, 'Well, isn't it better for everyone if I die now'—even if their families are not pressuring them directly. Tragically, there may well be cases where they are showing that they do not want to. But even in cases where their families are loving elderly people will know that they are a burden on their families. We think that the societal pressure that will come when euthanasia is legitimised by legalising it will mean that in many cases it will not be a genuine choice.

Mr Shelton: If I could add something else. A few years ago I was speaking with a member of this parliament who said to me, 'Well, euthanasia is already happening.' I asked what was happening and this member of parliament said, 'Pain relief is being administered in a way that hastens death.' I said, 'That is not euthanasia. That is just the proper care of someone who is suffering.' I think there are a lot of misunderstandings about what euthanasia is, and I think that anecdote certainly proved that.

Senator DI NATALE: How many times has the federal parliament attempted to enact euthanasia laws?

Mr Shelton: We have a list here: 2008, 2010—

Senator DI NATALE: The federal parliament.

Mr Shelton: Commonwealth parliament, yes. There was the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008—

Senator DI NATALE: That was to repeal the territory laws.

Mr Shelton: Correct.

Senator DI NATALE: How many times has the federal parliament attempted to introduce euthanasia laws?

Mr Simon: There were two previous attempts in the federal parliament.

Senator DI NATALE: How many times has the federal parliament attempted to introduce federal euthanasia laws?

Mr Shelton: The term used was 'legislative attempts to bring about euthanasia'.

Senator DI NATALE: But how many times has the federal parliament attempted to introduce euthanasia laws?

Mr Simon: Until now, none.

Senator DI NATALE: This is the first time?

Mr Simon: That we are aware of.

Senator DI NATALE: It hardly sounds like reform by fatigue, does it?

Mr Shelton: There is a list of 10 here that I happy to table—

Senator DI NATALE: It is the first time the federal parliament has attempted to introduce euthanasia laws.

Mr Shelton: With respect, Senator, there have been two attempts to revive the territory legislation. I guess we are talking about using the mechanisms of the parliament and parliamentary time to achieve a political agenda.

Senator DI NATALE: How many times has the federal parliament attempted to enact its own euthanasia laws?

CHAIR: I think you have asked that and it has been answered.

Senator DI NATALE: It is the first time, isn't it? The reason I am labouring this point is that it is unusual for a witness to come in and make such a partisan statement—which you did—in your opening remarks. I am pointing out to you that this is the first time the Australian parliament has attempted to enact euthanasia laws. Tell me about the only jurisdiction where euthanasia laws were enacted?

Mr Shelton: That was in the Northern Territory.

Senator DI NATALE: Who introduced those laws?

Mr Shelton: It was the Country Liberal Party.

Senator DI NATALE: Did you make mention of the Country Liberal Party in your opening statement?

Mr Shelton: No, but I am quite happy to.

Senator DI NATALE: No, because your opening statement was directed at the Greens. I need to make this point, Chair, because—

CHAIR: Senator Di Natale, I agree with you. I thought the opening was perhaps a bit pointed. But we are not here to play politics. We are here to investigate it. No harm has been done. Let us just move on to the substantive—

Senator DI NATALE: The point is that the opening statement tried to create an environment to suggest that this was an initiative of the Greens and was supported by no other political parties and that in fact we have been here and done that many times. Well, the federal parliament has never attempted to introduce its own laws. The only jurisdiction in which these laws have ever existed in Australia is the Northern Territory where they were introduced by the Country Liberal Party. The Greens had nothing to do with it. Are you aware that the proposed bill in the Northern Territory was introduced conjointly with the Australian Labor Party?

Mr Shelton: I was not aware of that. That was 1996.

Senator DI NATALE: If you are going to come in here and make such a partisan attacks, make sure you have the facts in front of you.

Mr Shelton: I am very happy to table our list. The reality is that the last two attempts to revive euthanasia laws were by the Greens political party, using the mechanisms of the Commonwealth party to restore that. So it is just a statement of fact. Yes—

Senator DI NATALE: It is not a statement of fact. Your statements were, in fact, quite misleading.

Mr Shelton: I do not think it is misleading. The Greens have been leading the charge on this.

Senator DI NATALE: Let's move on.

Mr Shelton: I think you would agree with that, with respect.

Senator DI NATALE: I am quite happy to be advocating for the—

CHAIR: Order! We are really here to inquire into the legislation before us. That requires us to ask questions of the witnesses about the bill or about their submission.

Senator DI NATALE: I am happy to move on. It would have been nice if that was the spirit in which the opening statement was conducted. You quoted Julia Gillard and her opposition to these laws. Do you also agree with Julia Gillard about her support for the rights of women to have a termination?

Mr Shelton: No, I do not agree with those. I do not have to agree with everyone on every issue to quote them. That is not the issue that is before this committee, with respect.

Senator DI NATALE: Let me ask you about the question of pain and suffering. In fact, I think you quoted a statement I made. I cannot remember when I made it. Was that made in the parliament?

Mr Shelton: Yes, it was. It was a speech on a matter of public interest. It was on medical marijuana and euthanasia.

Senator DI NATALE: Yes, I recall that, now. I was quite proud of that, actually. Do you not accept that that is the situation that confronts many people who are dying?

Mr Shelton: I accept that it may confront some people, but as I talk to palliative care experts such as Dr Van Gend, these are conditions which are readily treated with proper palliative care and I think—

Senator DI NATALE: On that point, we have a palliative care physician as a witness to this inquiry, and we have had other submissions that have made it very clear that in some settings palliative care cannot relieve people from quite severe pain and suffering. That scenario, where somebody is lying in a hospital bed, with tubes sticking out of all sorts of body parts, often drowning in their own secretions, sometimes incontinent fecally, in an induced coma because the available palliative options are unable to relieve them of their pain and suffering is a reality. Do you accept that?

Mr Shelton: I accept that that can be a reality for some people. I do not come here, for one moment, saying that for some people there is no pain and suffering associated with death. I do not say that that can be eliminating in all cases. But I am advised that in many cases—in the vast majority—they can be treated with proper palliative care.

Senator DI NATALE: Correct. Absolutely. On that point we—

Mr Shelton: I guess that is our problem with euthanasia. We are using examples of very hard cases to make law and to make public policy which then has quite a profound cultural ramification and brings about the sorts of pressures and abuses that we have been talking about here today.

Senator DI NATALE: But you acknowledge that there are people out there—

Mr Shelton: Yes, I do.

Senator DI NATALE: The example I have mentioned is one that happens all the time. Somewhere between one and five per cent of people in palliative care will be in there under terminal sedation, drowning in their own

secretions, incontinent fecally, starved of hydration and nutrition and dying a very slow, agonising and undignified death. Do you accept that that is a consequence of—

Mr Shelton: I accept that that may well happen, but I am also advised—

Senator DI NATALE: So you do accept that.

Mr Shelton: I accept that that may happen. I am also advised that it can be treated with good palliative care.

Senator DI NATALE: No, that is different. Most people do not go through that. I agree with you. In fact, most people, if given the choice, will choose the palliative option. And it will be a very positive experience for them and their family. That is undeniable. And that is the case for the vast majority of the community who go through that experience. And we need to keep investing and resourcing that. But for a small group of patients it simply does not work. In fact, we have to put them into an induced coma. That scenario I described to you, where they starve slowly, being incontinent and being unable to breathe, sometimes vomiting, is a reality for some people.

Mr Shelton: Yes, I am aware that that is a reality for some people, but I do not think that that is justification for euthanasia.

Senator DI NATALE: Do you think that those people are looking, and I will use your quote, 'to seek death as a way out'?

Mr Shelton: Well, I did not use that quote.

Senator DI NATALE: It is in your submission.

Mr Shelton: That is more broadly with regard to euthanasia.

Senator DI NATALE: No, but they are the people we are talking to.

Mr Shelton: Well, I do not know. I think the debate is broadened beyond that particular minority cohort of people.

Senator DI NATALE: But do you think that person is trying 'to seek death as a way out', to use your exact words—the words you used in your submission?

Mr Shelton: In that very minority cohort, possibly not, although I cannot—

Senator DI NATALE: So why would you say that this is a way of seeking death as a way out?

Mr Shelton: Because that is the sort of culture that is created with euthanasia. We gave these examples that have been quoted from the international media, and I am quite happy to provide you with the list of those, because this is the sort of thing that tends to happen and we see it well demonstrated in the Netherlands and Belgium.

Senator DI NATALE: Clearly in the Netherlands and Belgium you have studied that legislation and you have studied this exposure draft. Please tell me how they are similar?

Mr Shelton: Our understanding of the Belgian and Dutch legislation is that there are supposedly safeguards. People are meant to be terminally ill.

Senator DI NATALE: What are the safeguards in those pieces of legislation?

Mr Shelton: Well, that you have to be terminally ill, but obviously that is not occurring in many cases, and it is supposed to be informed—

Senator DI NATALE: No, that is not a safeguard; that is a definition. What are the safeguards in the Belgian legislation and the Dutch legislation? You are making a comparison and you are saying this is the consequence, that this is what will happen here. Tell me about the safeguards in the Dutch and the Belgian legislation.

Mr Shelton: My understanding is that you have to be terminally ill and in intolerable suffering.

Senator DI NATALE: That is not a safeguard.

Mr Shelton: It is a safeguard. That is a big safeguard from abuse.

Senator DI NATALE: That is a definition through which someone applies to have the legislation applied.

Mr Shelton: We might have to agree to disagree on that.

CHAIR: This is really not a debate. When you ask a question, allow the witness to finish his answer before you ask the next one. Mr Shelton?

Mr Shelton: As I said, that safeguards are that someone has to be terminally ill and in intolerable pain. And I think there is demonstrable evidence, certainly from media reporting, that that is not always the case.

Senator DI NATALE: How many medical professionals are they required to see?

Mr Shelton: I cannot give you the exact detail of that, and I am sure that is the answer you are looking for.

Senator DI NATALE: So how do you make a comparison between what happens there and what happens here if you are not sure of what the safeguards actually are in both circumstances?

Mr Shelton: It is known that those safeguards are meant to be in place.

Senator DI NATALE: What safeguards?

Mr Shelton: Well, as I said—

Senator DI NATALE: Do they need to see a psychiatrist in Belgium and the Netherlands?

Mr Shelton: I cannot give you that detail, but I know that that is often—

Senator DI NATALE: Don't you think that is important?

Mr Shelton: I do think it is important; it is very important—

CHAIR: Senator Di Natale, please do not interrupt. If you ask a question you have to let the witness finish, even though you do not like the answer, and then you can ask another question.

Mr Shelton: I do think it is important. I cannot give you the exact detail of every criterion that must be met in terms of the Dutch and the Belgian legislation, but I do know that terminal illness is a requirement, and intractable pain. I do know that in many of the attempts—and we have a list of the various legislative attempts that have been made with euthanasia—most the bills do require people to see a psychologist and to go through those things.

We have had advocates questioned in previous parliamentary inquiries. It would be worth having a look at the *Hansard* from the 2009 parliamentary inquiry to see where a leading euthanasia advocate said that he would prefer for those safeguards not to be in place, that he finds them an impediment and that people should be able to freely die without having to jump over those hurdles. I accept that that is not everyone in the euthanasia community, but that is certainly one leading advocate.

Senator DI NATALE: That has nothing to do with the bill we are talking about. There are a lot of people in the euthanasia community who say things I do not agree with as well. The reason I make that point is that you gave a number of examples to highlight what will occur if this bill is passed, yet you cannot tell me how both of those bills—the bills that we have here and the bills that we have in the Netherlands and in Belgium—differ or are similar. Now, I can tell you that the requirement to see two doctors and a psychiatrist is not a feature of either of those pieces of legislation. Would you like to make a statement about whether you think it is valid to make a comparison when you are talking about two very different sets of legislation?

Mr Shelton: I think it is a valid comparison, particularly given that the sorts of safeguards that you are speaking about today were actually legislated as part of the Country Liberal Party and Labor legislation in the Northern Territory. The chief proponent of that legislation, who was administering euthanasia when it was briefly legal, admitted freely to breaching that, and there was no action taken against him despite him admitting that in an article that he co-authored in *The Lancet* medical journal. I am amazed that it has taken so long for that individual to receive some sort of sanction. I guess my point is that, when those so-called safeguards have been in place, as they were in 1996—and that is why I raised that in my opening remarks—they were circumvented. When he was questioned about that at the 2009 parliamentary inquiry, he admitted to the breach of the Northern Territory legislation and said, 'It was a breach motivated by compassion.' Why wasn't something done? Why was it only this year that he was struck off as a medical practitioner?

Senator DI NATALE: So your argument is that we should not pass a law because someone might break it?

Mr Shelton: I think we have to be clear that the trends we have seen in other countries, which supposedly have safeguards, and admittedly perhaps not all the ones that you intend, are freely circumvented. We are seeing this with seeming regularity, according to international media reports, and I do not think we can dismiss that as part of this debate.

Senator DI NATALE: If we were to introduce this, people might break the law. What is stopping people from breaking the law now?

Mr Shelton: That is a hypothetical.

Senator DI NATALE: It is not a hypothetical. It is happening at the moment. We know that.

Mr Shelton: I am not sure how that is relevant.

Senator DI NATALE: I think it is perfectly relevant. Your argument is: we cannot pass this legislation because some people might break the law. We have a situation at the moment where people are breaking the law.

Mr Shelton: We had someone break the law and admit it before a parliamentary inquiry, and no action was taken.

Senator DI NATALE: We have had people who have admitted it before police and no action has been taken. At the moment, we have a GP in Victoria who has admitted quite openly, 'I have provided people with medication to help them end their life'—in the absence of any legislation. I do not see how an example of where somebody is breaking the law, should this law be passed, is any different to what we have at the moment.

Mr Shelton: I know that proponents of legislation like you do not like these slippery-slope arguments, but we have clearly seen the slippery slope well and truly in action in Holland and in Belgium, in particular, where we have seen people being euthanised without their specific consent. That is not voluntary euthanasia.

Senator DI NATALE: I think I have probably exhausted my questions.

CHAIR: I will just mention that we do have with us via teleconference Senator Leyonhjelm. Are you with us, Senator Leyonhjelm?

Senator LEYONHJELM: I am; I am here.

CHAIR: You would not be aware, but the final witness on the suggested agenda is not now appearing today. We hope to get them some other time. Do you have questions that you wanted to ask of our final witness, which is the Australian Christian Lobby?

Senator LEYONHJELM: The danger is that this ground will be covered. But, with your indulgence, Chair, tell me if this has been—

CHAIR: I think you have probably heard most of Senator Di Natale's questions, and you may not have got all of the opening statement of the Australian Christian Lobby but you probably have read their submission and it was along the lines of what they said there. Fire away and ask your question, and then we will come to Senator Ketter. We have only got about 10 minutes left, so it is over to you, Senator Leyonhjelm.

Senator LEYONHJELM: All right; I will be brief. The most common objection that I have heard to this proposal, which I call assisted suicide, is that it is the thin end of the wedge that opens the door to worse things. Is that your argument, as well? Is that your proposition—that it is just the beginning of a slippery slope?

Mr Shelton: Certainly, that is a large part of our objection, yes—not entirely but a large part of it.

Senator LEYONHJELM: If the intent of the legislation could be achieved so that it was restricted to people who had a clear view of what they wanted to happen with their life, and it could not be misused and there was no scope for expansion of it, would you still oppose it?

Mr Shelton: Yes, I would, and that would be on grounds of my understanding of the dignity and the inherent worth of all human life. But that is not an argument that I would seek to necessarily expect the Senate to accept. I think that the scenario you have painted would be—with respect—near impossible to achieve. Once you go down this path, it is very hard to regulate the motives of people, whether it is family or others. There are very complex human motivations that come into end-of-life issues, and I do not think there is any way that is practical to enforce what you have suggested. And I think in reality you would be talking about this being available to a very, very small cohort of people who would fit a very narrow definition of what was acceptable. And then I think the question goes to whether hard and difficult and tragic cases make good public policy, good law, and I think generally we find as a principle of public policy that hard cases do not make good law.

Senator LEYONHJELM: What are your views on suicide per se, in the absence of assistance? Does somebody have a right to end their own life if that is their choice? Or do you think the law should prohibit that?

Mr Shelton: I believe the law should prohibit that. I realise that may not be in accord with certain political ideologies, but I think it is very dangerous to take away that prohibition in law. The law is a teacher, and I think that is an important safeguard that we have in civil society—having a prohibition legally on suicide.

Senator LEYONHJELM: Perhaps I could ask you to explain the foundation for that attitude. The contrary argument that I would put to you is that you own your own life; your life is not owned by somebody else, and certainly not by the government, which makes laws. Therefore, whether you choose to end it or not should be your choice, not anybody else's. How would you counter that argument?

Mr Shelton: I think all of us from time to time make choices that we regret. We can all find ourselves in situations perhaps where we are feeling depressed, where we are not in a normal state of mind for ourselves. And yes, by all means, we can freely make a choice, but one that is a poor choice, and I think if you lift the prohibition on suicide you increase the danger of making a choice that they have no possibility to rectify.

Senator LEYONHJELM: How far do you extend that? Is it the role of the law to prevent us from making decisions we might regret as a general principle? Or are there some that are okay and some that are not okay?

Mr Shelton: These are very difficult and philosophical questions, but from what I understand of the political philosophy of your party, if I can say so with respect—and I do not pretend to be an expert on libertarianism—I do see some dangers in extreme libertarianism. I think civil society does provide some important counterweight and counterbalances to extreme individualism, and I think extrapolating individualism to its length is not healthy for a civil society. It does have an impact on other people, as much as we might think it affects only the individual involved. It is the old phrase 'no man is an island'. It is a case of balancing individual freedoms with I guess our obligations to each other as a society.

Senator LEYONHJELM: Where do those balances fall? You did not really answer my question. If suicide is in the category of a decision that we might regret and therefore the state is entitled to prevent us from making that decision for ourselves, then what other decisions that we might regret is the state not entitled to prevent us from making? Do we include smoking? Eating fatty food? Refusing to do exercise? Where does the pendulum land?

Mr Shelton: People of good faith have argued about where the balance should be struck for a very, very long time. I would not pretend to say where it should be struck, but there should be a balance, and I guess that is the responsibility that you as legislators have.

Senator LEYONHJELM: So, there should be a balance; we do not know what that balance is; but you are sure that suicide is on the negative side of the balance.

Mr Shelton: Yes, I am, and I would say the same for euthanasia, for the reasons we have articulate. Very complex human emotions come into this, and motivations, and a whole range of things, and once you step over a line legislatively you affect the culture and you affect people's sense of obligation to society—whether they are being a burden. You affect people's motives in terms of perhaps nefarious motivations towards an estate. A whole range of very complex motivations come into play. That is why I think we need the sorts of safeguards we have traditionally had—and that the vast majority of nations in the world have—when it comes to euthanasia.

Senator LEYONHJELM: I am just trying to explore this area of decisions we might regret and the role of the government in preventing us from making decisions we might regret. I am trying to understand. So far you have nominated two issues that fall into that category. I am just wondering what else you would—

Mr Shelton: You mentioned smoking and eating fatty foods. I accept what governments of all political persuasions do to discourage smoking. It has a demonstrable impact on the public health budget and on people's health. I think it is good that we as a society dissuade that, and that is done through the democratic process. So I guess this is the way we try to achieve a balance. It is through free argument in places like this parliament in the public discourse. I am not saying that there is always a perfect place to strike the balance, but a balance must be struck. That occurs through the democratic processes, and I think that is the great features of Australian democracy.

Senator LEYONHJELM: Yes, I accept that, but we are talking about the power of the law—the power to arrest you, prosecute you and send you to jail if you break the law. So I am trying to understand in which cases—what examples there are. You are saying that it should be against the law if somebody attempted to commit suicide. Should they be arrested and prosecuted and so forth? If they did something else that would fall into your category of a decision they might regret, and the law was involved, the same process would kick in, so there would be prosecution and so forth. What I would like to understand is not just about the government persuading you and arguing that this is not a wise decision. I am talking about prosecution. So, I would like to understand where you think the pendulum should land.

Mr Shelton: With respect, I think this is very hypothetical. But obviously in terms of suicide, that is a final decision, and there is no opportunity for regret. As for where the balance should fall for other decisions that individuals might make that have consequences, I guess that is something that civil societies need to weigh up in terms of legislation. The government does not have to regulate everything, but there are certain things that have greater consequences than others, and that is why we have a legislative process and why we have debate and argument and discourse to try to determine those things. I am sorry; I am probably not satisfying you, but I think you are asking very deep philosophical questions. I would love to sit down and chat with you later about them, but I am not sure that it is assisting the inquiry.

Senator LEYONHJELM: Okay. Thank you.

Senator KETTER: Senator Di Natale was asking questions of you previously about the safeguards in the bill that is before the committee. And you would be aware that it is required that two medical practitioners examine a person who is seeking voluntary euthanasia services and then a psychiatrist has to confirm that the person is not

suffering from a treatable clinical depression in respect of the illness. In your view, are those safeguards adequate?

Mr Shelton: If they are enforced, perhaps they could be, but we have seen these sorts of safeguards in the previous legislation that I mentioned in the Northern Territory, and they were not. I have certainly heard—and I am not saying that this is Senator Di Natale's position—that others on the euthanasia committee find these sorts of things offensive and an affront to people's free choice.

Senator KETTER: Are you familiar with the writings of Theo Boer of Holland?

Mr Shelton: No, I am not.

Senator KETTER: You have made reference to the Netherlands in your submission. There appear to be an increasing number of people in the Netherlands accessing voluntary euthanasia services. Do you have any knowledge of what is happening there?

Mr Shelton: My understanding is that it is growing. Do you have updated figures?

Mr Simon: Nothing more than that, no.

Mr Shelton: We understand that it has been on the increase, and we have submitted to previous Senate inquiries at a federal level that anywhere up to 1,000 people a year have been euthanised without their explicit consent in the Netherlands.

Senator KETTER: What do you know about the travelling euthanising doctors? Are you able to elaborate on that?

Mr Shelton: No. I am aware that there have been ships and things like that, but only what we have seen in the media.

Senator KETTER: Thank you. I have no further questions.

CHAIR: One of your concerns, as I understand you, is that even the most strictly written law to provide all of the safeguards that might ever possibly be able to be provided are unable to be properly enforced.

Mr Shelton: That seems to be the case. I accept that Senator Di Natale has sought to put greater safeguards into his bill, but there are safeguards in Belgium and the Netherlands, and it would seem from the media reporting, in reputable publications, that some of the basic requirements of the legislation are not being met after this has been in place for some time—twins being euthanised because they were going blind, et cetera. These have been very high-profile cases. I do not understand why these things are not enforced and why seemingly a blind eye is turned, and we have a proliferation of these seemingly inexplicable cases of people just committing suicide—nothing to do with euthanasia, but supposedly doing it under the euthanasia laws.

CHAIR: I must confess that I do not know the law in the Netherlands at all, but clearly the draft bill would not allow for termination of life because someone was going blind, as I read it.

Mr Shelton: And my understanding is that Belgian law does not allow that either.

CHAIR: As I said, I do not know; I take your word on that. Finally, I just want to say thank you very much for your submission and for your being here today. We do appreciate your coming forward and your help to the committee. So, thank you very much. In closing, I will say that we will try to get Dignitas at a future hearing, and apologies to them in their absence for messing them around a bit today.

Committee adjourned at 15:48