JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS REGARDING THEIR OWN END OF LIFE CHOICES



TRANSCRIPT OF EVIDENCE TAKEN AT PERTH FRIDAY, 13 APRIL 2018

SESSION THREE

Members

Ms A. Sanderson, MLA (Chair)
Hon Colin Holt, MLC (Deputy Chair)
Hon Robin Chapple, MLC
Hon Nick Goiran, MLC
Mr J.E. McGrath, MLA
Mr S.A. Millman, MLA
Hon Dr Sally Talbot, MLC
Mr R.R. Whitby, MLA

Hearing commenced at 11.30 am

Mr IAN WOOD

National Coordinator and Spokesperson, Christians Supporting Choice for Voluntary Euthanasia, examined:

The CHAIR: Thank you very much for joining us today. I am going to read the opening statement and we will start the hearing. On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson and I am the Chair of the Joint Select Committee on End of Life Choices. I would like to introduce the other members. We have Hon Dr Sally Talbot; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Col Holt; Hon Nick Goiran; and Hon Robin Chapple.

The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in Western Australia and to highlight any gaps that may exist. You have agreed to provide evidence to the committee. Your evidence is protected by parliamentary privilege in Western Australia and protected by uniform defamation laws in Australia against actions of defamation. Please note that these protections do not apply to anything that you may say outside of today's proceedings. It is important that you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. The audiovisual recording will be available on the committee's website following the hearing.

Do you have any questions about your attendance here today?

Mr WOOD: No, no questions.

The CHAIR: Before we ask any of our questions, did you want to make an opening statement for the committee?

Mr WOOD: I have got an opening statement. If I could have slide 1, please. Christians Supporting Choice for Voluntary Euthanasia is a group formed in February 2009 by Reverend Trevor Bensch and myself. Before my retirement in 2000, I was a community pharmacist in Port Pirie, South Australia, for almost 40 years. Since retirement, apart from operating our group, a key interest has been entertaining at aged care and adult day care centres singing golden oldies with a friend or as a family quartet, with my wife at the piano. It is significant that as I began preparing this statement, Hawaii became the seventh US state to pass an assisted dying choice law with the aptly named Our Care, Our Choice Act. In our small way, we, Christians Supporting Choice for Voluntary Euthanasia, represent the vast majority—70 to 80 per cent—of Australian Christians who support compassionate choice in dying for those with unbearable suffering and no hope of recovery. I know that there are some who doubt this level of support, but there are similar high levels in Canada, where they now have this choice as a basic human right, and in the UK, where wealthy people can fly to Switzerland for assistance, but nobody can get the choice where they live.

Can I have slide 2, please. Archbishop Desmond Tutu is a strong supporter of assisted dying, and he says —

"As a Christian, I believe in the sanctity of life and that death is part of life.

I hope that when the time comes that I am treated with compassion and allowed to pass on to the next phase of life's journey in the manner of my choice," ...

He also said —

"My friend, Lord Carey —

In case you are not aware, Lord Carey is the former Archbishop of Canterbury, the head of the Anglican community —

has passionately argued for an assisted dying law in the United Kingdom. His initiative has my blessing and support ... People who are terminally ill should have the option of dignified and compassionate assisted dying, alongside the wonderful palliative care that already exists," ...

"I pray that politicians, lawmakers and religious leaders have the courage to support the choices terminally ill citizens make in departing Mother Earth with dignity and love."

Can I have slide 3, please. There are some Christians, obviously, who are vehemently opposed to any form of assisted dying. In the lead-up to the 2017 WA election, we emailed candidates asking for their position on the question whether a terminally ill patient facing unbearable suffering should have the right to choose a medically assisted death. The following is an extract from the response of Rosemary Steineck, candidate for the Australian Christians party. She says, "A woman who was dying of a terminal highly invasive spinal form of bone cancer, producing increasing agony, which could not be palliated by normal pain relief. She was two months in dying." Rosemary continues, "Why could not the doctor, with her permission, sever her spinal cord above the site of the cancer? She was dying anyway; there was no possible question of saving her life. Yes, she would have become a paraplegic. Yes, she would have been confined to a wheelchair, but would that really have mattered so much at the end of her life? She could have died pain free." My comment on that is: how utterly barbaric. Obviously, Rosemary would never be a member of our group. Another candidate suggested that an assisted death would give their wayward dying uncle less time to return to the Lord. Notable is the fact that 89 per cent of all responses supported the question. I have not studied every submission, but there are clear trends. Those who have had a relative or friend die a horrible death support voluntary assisted dying. Of those against, some are Christian but do not state that clearly in their submission, and many use a form-type letter citing the alleged vulnerable, elder abuse, the slippery slope, a Southern Medical Journal article on suicide contagion, and use the emotive word "killing".

Can I have slide 4, please. Opponents often cite suicide contagion to suggest that the legalisation of VAD will result in an increase in suicides generally, as evidenced by Oregon's high rate of suicide. As, I believe, Neil Francis, from Dying for Choice, points out, this is a deliberate, and false, conflation of two very different acts. Suicide contagion cannot explain why the US states above the green line, including Wyoming and Alaska, which do not have an assisted dying law, have much higher rates of suicide than Oregon, which has offered assistance to terminally ill Oregonians since the 1997. Deaths under the act in Oregon are a choice between two different ways of dying, unlike general suicide, where the choice is between living and dying.

A number of submissions against VAD refer to "do no harm" from the Hippocratic oath. Medicine has progressed since around 400 BC, when doctors swore the Hippocratic oath to the Greek god Apollo—a doctrine that forbade surgery and women from becoming doctors. Medical schools no longer require graduates to take anything like this oath. I submit that allowing a person to die with terrible suffering because of a refusal to permit an assisted death is in fact doing harm. As noted in my submission, even the best palliative care is inadequate for a small, but very important, group of

dying people. One troublesome factor, even with good palliative care, is that any patient has to experience some considerable degree of suffering before anything like adequate relief is given. The tragic death of Clive Deverall, the WA person involved with both palliative care and the Cancer Council, indicates the inadequacy. Notable too is the terminology. For example, "breathing problems" in a Palliative Care Outcomes Collaboration chart can mean horrific feelings of choking, strangulation or drowning in your own saliva—not just being out of puff from walking uphill.

[11.40 am]

Can we have slide 5, please. Here we have Tim, who died recently of mesothelioma shortly after Tim and I visited our local MP in support of VAD. An article in the DWD New South Wales autumn newsletter by Jessica Edwards, daughter of Tim, includes —

In the end, Tim's position on assisted dying worked strongly against him, with his palliative care doctors and nurses, in my view, undertreating him and one of them repetitively lecturing a grieving family about the illegality of assisted dying (even the day before he passed away). In the final days of his life, we took turns sitting with him and watching him sleep. At one point he woke up, looked at me and asked "when are they going to let me go". All I could do was look at him in tears and say "I don't know—this is not the way it should be".

Could I have slide 6, please. AMA president, Dr Michael Gannon, on the AMA website says —

If we look at the international experience, the Dutch experience is that euthanasia has become a common way for people to die.

I query that "common". It is not really correct; 95 per cent of all deaths in the Netherlands are not euthanasia. Gannon continues —

When you look at the most common demographic in the Netherlands, it is single women over the age of 50 that do not have cancer, that do not have a chronic disease. That is how these laws have extended in other parts of the world.

We can see that this graph. It shows that 73 per cent per cent of the people who died had cancer and the rest had significant and/or chronic health conditions. Also, of course, Dr Gannon's example is quite irrelevant to Australia as the eligibility criteria in the European model has always been broader than the American model on which the Australian bills are based because they allow "unbearable and irremediable suffering" as a criteria for accessing assistance, whereas the American laws, as you know, require a terminal illness.

Finally, it is excellent that Victoria has passed laws for voluntary assisted dying. While I think, ideally, universal legislation Australia-wide should be the option, there are some problems that I perceive with the Victorian law. They include the time scale of six months generally for access, and nine days' wait between first and final request. There are some restrictions preventing doctors initiating discussions on VAD, and that seems ridiculous to me. It should be part of the necessary overall discussions on all end-of-life options between the patient and the doctor, and, indeed, this is one of the unforeseen benefits of the VAD legislation in Oregon et cetera and Canada. To sum up, the three key words are "voluntary", "compassion" and "choice". Thank you, and I look forward to any questions.

The CHAIR: Thank you very much, Mr Wood. I appreciate your evidence this morning. Could I ask first of all how many members your group has?

Mr WOOD: We have about 1 100 members. We could get more, but I find the scale of our operation hard enough to manage now. Half of our membership do not even have email, so we have to contact them by snail mail and that can difficult.

The CHAIR: Yes. I also want to ask you: are you currently based in Victoria?

Mr WOOD: No. I am living in New South Wales.

The CHAIR: We have seen bills recently introduced into both the New South Wales and Victorian Parliaments. Does your group have a view on each of those bills?

Mr WOOD: I am delighted that Victoria has passed the bill. There were two problems that I mentioned with trying to determine how long the patient has to live as a criteria for accessing help. To me, the key thing should be the degree of suffering that that patient feels rather than being restricted to a timescale. On the other hand, I think that in an ideal situation—and it is not a slippery slope—type argument—as time goes by, the act will be reviewed with a view to saying, "Well, what problems have we got here? Can we solve them?" and go from there.

The CHAIR: The committee has heard some evidence about protecting vulnerable groups and safeguards, in particular older people who may be under some duress. Do you or your membership have a view about what safeguards would need to be in legislation to protect elderly people from duress?

Mr WOOD: I think the current safeguards are fairly similar. In legislation almost universally, you have the two doctors that need to assess the person for competence and coercion, and as far as competence goes, my doctor assessed me for competence to drive and retain my driver's licence just the other day. That included assessing me for dementia, cognitive issues and mental health. Those were part of the tick-boxes in the forms that you had to fill out.

The CHAIR: The other aspect of this inquiry is advance health directives.

Mr WOOD: Yes.

The CHAIR: Do you have a view as to how well they are utilised and what your members' experiences are of them?

Mr WOOD: I certainly think they are underutilised. I have had one myself for some considerable number of years. I have two, actually—one specifically dementia and one general one. I think they tend to be underutilised and I think that a lot more needs to be made of the use of them and the availability of them. As far as experience goes, one member in particular comes to mind. Her husband was in the last stages of uncontrollable vomiting from a blocked bowel and she describes how the nurse came into the room reading this person's advance care directive in tears, saying she was sorry that she could not do more to stop this person's suffering in the last hours of that person's life. That memory has remained with that woman ever since.

The CHAIR: Noting that each state has a different form of advance health directive, as a principle do you have a view as to why they are underutilised?

Mr WOOD: Possibly it is partly to do with the medical system. As I said, I have had mine done for some years and I have actually got it registered with the medical clinic that we attend, but when I was seeing another doctor at that place, I actually asked her—she did not know me, really—what was her opinion on advance care directives. She just said that she did not think you needed to bother about them until you are in a nursing home. It was interesting at that time, because there was a medical student in the same room as me having training and I said to her, when the treating doctor actually had to leave the room for a minute, "What are you taught about advance care directives?"

She said, "We're taught that they should be available and used by everybody at every age, because you never know when a person's going to have an accident that might require the use of that."

Hon ROBIN CHAPPLE: Following on from that, Dr Wood —

Mr WOOD: I am not doctor; I am just mister! I am a retired pharmacist.

Hon ROBIN CHAPPLE: I do apologise. I am elevating you to a status you do not have!

Mr Wood, in relation to advance healthcare directives, are you aware of any significant difference between advance healthcare directives in different states? It is most probably something we have not actually looked at.

[11.50 am]

Mr WOOD: I cannot say that I have really examined in detail the difference between the directives. I do know that when I had one in South Australia before I moved to New South Wales six years ago, we had to update it to sort of make it more relevant to New South Wales. It seems to me, in the ideal situation, I guess that is up to our politicians if we will have the same advance care directive throughout Australia.

Hon ROBIN CHAPPLE: Thank you.

Hon Dr SALLY TALBOT: Mr Wood, I just want to ask you a couple of theological questions.

Mr WOOD: Yes.

Hon Dr SALLY TALBOT: You are not a theologian, are you?

Mr WOOD: No.

Hon Dr SALLY TALBOT: You are a practising Christian rather than a theologian.

Mr WOOD: Yes.

Hon Dr SALLY TALBOT: I hope you will bear with me. We have heard from other representatives of faith-based organisations in this inquiry, as you probably know, because you would have been following it. One of the things that has been raised with us is this concept of the sanctity of human life.

Mr WOOD: I think Desmond Tutu covered that quite well when he said that life is sacred—I forget his exact wording now—but there are limits and the sanctity of life should not prevent a person from dying if you spare suffering.

The CHAIR: Could you just repeat that again, Mr Wood?

Mr WOOD: I will try to.

The CHAIR: No; it is more the audio rather than what you said, so just repeat that for us.

Mr WOOD: It is important that everybody believes that life is sacred, but that should not prevent a person from accessing assistance who is suffering severe pain and has got no prospective future.

Hon Dr SALLY TALBOT: Thank you. The second question I want to ask you, which is perhaps a little less theological, is about that faith-based concern—I stress faith-based rather than political—with vulnerable people. Do you have any comments to make about that? You understand what I am asking?

Mr WOOD: Yes, I think so. I tend to think that the truly vulnerable are the people who are denied a choice in dying by some of these very faith-based people. They are truly vulnerable; they are the ones who are needing help and pleading for it and, in some cases, asking for God to help them die, yet these other faith-based people are saying, "Well, I don't believe that you've got the right to

practise what you believe; my belief that voluntary assisted dying is wrong should take precedence over everything."

Hon Dr SALLY TALBOT: Thanks, Mr Wood.

The CHAIR: When you talked about accessing it when people are in pain and suffering, do you distinguish between existential pain and suffering and physical pain and suffering?

Mr WOOD: I think probably either are important. I have read some horrific stories of what Julia Lawton in a book of hers calls the "unbound body". This is where a person perhaps has some internal disease and their body can be rotting from the inside while they are still alive. This is the sort of thing—people should have the choice again. Obviously, any degree of suffering is going to cause some sort of degree of depression and that is not the sort of depression that we are talking about, say, with mental illness or whatever. I am not sure if that answers your question.

The CHAIR: Yes, it does. Do you think that there are people who should be excluded from accessing voluntary assisted dying?

Mr WOOD: I think we need to be pragmatic about this. I am inclined to people who have got the Swiss system where there is no regulation virtually by law at all. It is just a matter of demonstrating that they have brought in their own regulations to say what the criteria are and how the person has to have the medical records to show at the time so they are known to qualify. As far as exclusions go, I think terminal illness is adequate at the moment but, of course, terminal illness does need to include motor neurone disease, Parkinson's, multiple sclerosis and so on. This is where you have a problem with the timescale and this is why I think in an open situation, it should be the patient's own assessment—in the end the amount of their suffering should be the ultimate deciding factor about whether they can access this.

Hon NICK GOIRAN: Mr Wood, you have just responded to the chair indicating that terminal illness is enough for the moment. What do you mean by for "the moment"?

Mr WOOD: I suppose one key problem is the issue dementia, which is described by Alzheimer's Australia as a terminal illness, but as you would know, the prognosis is very difficult to predict. My mother died from it after about eight years. Her last couple of years were pretty terrible, but on the other hand I can understand that a person is no longer competent once they have progressed into dementia issues, so they cannot really request assistance. Now, building around that to a certain extent is the fact that a person can ask for assistance in the window between the first diagnosis of the dementia and before they pass into the next stage of being incognitive. One of the stories that I am familiar with is the one of Hugo Claus, an author who was about in his 90s, I think. He found he could no longer write a coherent sentence. He became able to access help to die. There is this quote from a Terry Pratchett documentary. His wife says, "He took the medication and he lay down and I started to sing to him and the patient died and he joined in the song as he was dying." As I said in my opening, I love singing myself and I could not think of any better way to die with dementia than to die singing with an assisted death. I think we should start small, possibly start with a very tight bill, and, as society progresses and the demand and the logic is there to expand slightly, well then that is the prerogative of Parliament.

Hon NICK GOIRAN: So, Mr Wood, you are a supporter of the slippery slope, then?

Mr WOOD: That is not the slippery slope.

Hon NICK GOIRAN: You would like to describe it in some other fashion?

Mr WOOD: I think there is a difference between a slippery slope, which is where somebody alleges that a progression from one state to another is inevitable.

Hon NICK GOIRAN: Right, because I thought I just heard you say that we should start small and then continue to progress.

Hon Dr SALLY TALBOT: That is not a slippery slope.

Mr WOOD: If society suggests and the Parliament agrees that we should have it available in a wider form.

[12.00 noon]

Hon Dr SALLY TALBOT: The slippery slope is actually a technical definition of the way of arguing that is false. Mr Wood is exactly right.

Hon NICK GOIRAN: I am intrigued by the distinction that is being drawn by both Mr Wood and my colleague. Nevertheless, do you have a copy of your submission available?

Mr WOOD: Yes.

Hon NICK GOIRAN: In your submission, you respond to the argument that where euthanasia exists, less emphasis is placed upon palliative care services, and you refer the committee to the Belgian budget for palliative care before and since physician-assisted suicide. You note that when, in 2002, Belgium legally regulated this, the passing of the law was preceded by a doubling of the federal budget for palliative care.

Mr WOOD: That is correct.

Hon NICK GOIRAN: Indeed, you quote from Bernheim et al in 2008 where they say—this is on page 4 of your submission —

Support for this boost was unanimous because the merits of palliative care were undisputed and physician-assisted dying, for which legal regulation was then in preparation, was widely considered unethical if requested and carried out for lack of available professional palliative care. Concomitantly with the law on euthanasia, a law was enacted to ensure universal access to professional multidisciplinary palliative care ... This law made palliative care a citizen's right.

Mr WOOD: Yes.

Hon NICK GOIRAN: Do you agree with the Belgian position, which you quoted?

Mr WOOD: Canada, when they passed their assisted dying law, also, as I understand it, increased their palliative care budget and access to palliative care. It is not an either/or situation between palliative care and assisted dying. They both should be complementary. Everybody should have access to good palliative care. Ideally, most people would like to die at home if they have that opportunity. Once again, that requires special palliative care services. But the idea is that if a person has suffering that cannot be relieved by active palliative care, then they have this additional choice. You have the other thing with terminal sedation. If a person is so sick with suffering that is so intense that they need terminal sedation, which is totally unregulated, there are no questions asked about whether a person has capacity or not. The doctor just decides that [inaudible] they will relieve the suffering and they will sedate them in a coma until they die. The end result is going to be exactly the same as if they had an assisted death; it is just that it takes a lot longer.

Hon NICK GOIRAN: So everyone should have access to palliative care?

Mr WOOD: Everybody should definitely have access to palliative care, and choice as well.

Hon NICK GOIRAN: That is interesting, because this committee has received evidence that 60 per cent of Western Australians do not have access to palliative care services that they need, and that rural access is especially problematic.

Mr WOOD: With due respect, that is up to the WA government to fix. I do think you could note that Oregon has one of the best palliative care systems in the United States and 90 per cent of the people who request an assisted death and actually proceed with it are also in hospice care of some type or other. Of course, the other question about Oregon is that one-third of the people who obtain the medication do not go on to use it. Having the right to an assisted death has enormous palliative value in its own right. If a person is facing a terrible death and they have this system lined up, I can assure you that I have had numerous instances where it is really just putting that person's mind at rest and they could go on living.

Hon NICK GOIRAN: I will just take you to my original question, which was whether you agree with the Belgian position, which you quoted at page 4 of your submission, that consideration of physician-assisted dying is unethical if requested and carried out for lack of available professional palliative care.

Mr WOOD: I think that palliative care should be available for everybody and it should be explained to them as an option.

Hon NICK GOIRAN: Yes, I know you did say that earlier. My question is whether you agree with the quote from Belgium, which is at page 4 of your submission.

Mr WOOD: That is why that palliative care budget was doubled. I am not sure of the availability of palliative care, but I am aware that every major hospital in Belgium, as far as I know, has some sort of hospice palliative care facility attached to it.

Hon NICK GOIRAN: So is it unethical or ethical?

Mr WOOD: I am not quite sure what you are getting at?

Hon NICK GOIRAN: I ask you to turn to page 4 of your submission where you quote and bring to the committee's attention the Belgium position where it says that consideration of physician-assisted dying is "unethical if requested and carried out for lack of available professional palliative care". My question is about whether you agree with that or not.

Mr WOOD: Right; sorry about that. I had two submissions and you are referring to the supplementary submission.

Hon NICK GOIRAN: Page 4.

Mr WOOD: Yes. I know Professor Bernheim personally. If he says that, I would agree with it.

The CHAIR: Sorry; I could not hear that, Mr Wood.

Mr WOOD: I know Professor Jan Bernheim personally and if he says in his statement that he would consider it unethical, then I tend to agree with him.

Hon NICK GOIRAN: Thank you.

Hon COLIN HOLT: Thanks for joining us, Mr Wood. I think that you are the first pharmacist—retired or not—to give some evidence. I know very little about pharmacy apart from going to get medication for myself, but would you regularly dispense drugs that in the wrong doses could kill people?

Mr WOOD: To the best of my knowledge, I have never dispensed a dose that would kill anybody. It is interesting that not that many years before I retired, we used to sell Nembutal capsules on prescription—bottles of 25. I wish I had kept a few myself. But, obviously, if a person took a large dose of those—not the indicated dose, which would have been one at night—that would have had the potential to take their life. In fact, that is probably one of the reasons why they went off the market eventually—because too many people were abusing them.

Hon COLIN HOLT: I understand that, in the right dosages—the prescribed amount—no-one is going to dispense drugs that, under the right prescription, would have an adverse effect. However, does a pharmacy have access to drugs that in doses could end someone's life? If they take an non-prescribed dose of a dispensed medicine —

Mr WOOD: A prescribed dose—well, nothing is going to end a person's life in a prescribed dose or it would not be prescribed.

The CHAIR: That is not the question. The question is—can you hear all right?

Mr WOOD: I think it is just a bit distorted at the moment. Could you repeat the question, please?

The CHAIR: Does a pharmacy have access to drugs which could end people's lives when they are taken in the not prescribed fashion?

Mr WOOD: Well, insulin is probably an example of such a prescribed drug. There is access to it but I would never suggest using it.

[12.10 pm]

Hon COLIN HOLT: You may or may not be able to answer this next question. Are you aware in your career as a pharmacist of people who you have prescribed medication for in the right amount actually abusing that prescribed amount and ending their life? You may or may not like to answer that, but I guess I am pursuing the idea of suicide and using a legal drug to bring about someone's own end of life. Are you aware of that in your circumstances?

Mr WOOD: I am not aware of anything like that. The closest I have come to that was with a person who was addicted to chlorodyne, which is a morphine containing compound that is no longer on the market. She would come into my shop and say, "Well, I need a bottle of chlorodyne." I said to her, "Well, you're having too much of this and so I can't sell it to you; I'm sorry." So she would go to another chemist in the town and ask for that. Eventually, all the chemists in the town got together and we said no, we were not going to supply her at all. What happened, unfortunately, is that she went to a neighbouring town and on the way back from there drove off the road, probably under the influence of too much chlorodyne, and killed herself. We did do our best to try to stop that, but she circumvented our precautions.

The CHAIR: Mr Wood, thank you very much for your evidence to the committee today. A transcript of this hearing will be forwarded to you for correction of transcribing errors only. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If a transcript is not returned within this period, it will be deemed to be correct. New material cannot be added by these corrections and the sense of what you have said cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence. Thank you very much for your evidence this afternoon. We really appreciate you taking the time to talk to us and for your submission to the committee.

Mr WOOD: I would like to thank you very much for the invitation to make the submission and to represent our group. I am very grateful to have had the opportunity to talk to you all.

The CHAIR: Thank you Mr Wood.

Hearing concluded at 12.13 pm