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
THURSDAY, 8 MARCH 2018

SESSION FOUR

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

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Hearing commenced at 2.25 pm

Miss JOHANNA BANKS
Research Officer, Coalition for the Defence of Human Life, examined:

Mr DWIGHT ALLAN RANDALL
President, Coalition for the Defence of Human Life, examined:

The CHAIR: Good afternoon to you both. Thank you for taking the time to join us this afternoon. 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; I am the Chair of the joint select committee. Committee members are Mr Simon Millman; Hon Dr Sally Talbot; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Col Holt; Hon Nick Goiran; Mr Reece Whitby and Hon Robin Chapple.

The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in WA and to highlight any gaps that may exist. It is important that you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege; however, this privilege does not apply to anything that you might say outside today's proceedings. I advise that the proceedings of today's hearing will be broadcast live within Parliament House and via the internet. The audio/visual recording will be available on the committee's website following the hearing. Do either of you have any questions about your attendance today?

The WITNESSES: No.

The CHAIR: Before we go to questions, did you want to make an opening statement?

Mr RANDALL: Yes, please. As mentioned, I am the president of the Coalition for the Defence of Human Life and as also mentioned, beside me is Johanna Banks, the research officer for the coalition. The coalition is a non-party political association comprising over a dozen different organisations that are vitally interested in matter relating to end-of-life choices. These organisations include: 40 Days for Life Perth, Association for Reformed Political Action, Australian Christian Lobby, Australian Christians, Australian Family Association, Christian Reformed Churches, Endeavour Forum, FamilyVoice Australia, Helpers of God's Precious Infants, Life Ministries, National Civic Council, Pregnancy Assistance and Westminster Presbyterian Church.

As practices that are deliberately intended to cause the death of the patient in Western Australia are illegal, the options currently offered to chronic and/or terminally ill patients are, in the Coalition for the Defence of Human Life's view, somewhat limited in scope but lawful and for the most part, good. The Coalition for the Defence of Human Life affirms that every Western Australian should receive competent and compassionate medical assistance throughout the end stages of their life. We believe that the solemn duty of health professionals is to heal, care for, nurture and preserve all human life and not to intentionally cause premature death. The Coalition for the Defence of Human Life supports the World Medical Association, WMA, and its national members, including the AMA, in their longstanding opposition to euthanasia and physician-assisted suicide even at the request of the patient or close relative. The WMA calls that unethical. That statement was made in October 2017.

The coalition also agrees with the WMA statement on physician-assisted suicide that it too must be condemned by the medical profession and that any doctor who assists in ending the life of a patient acts unethically.

The coalition supports the WMA's resolution on euthanasia that recommends that —

> … all National Medical Associations and physicians … refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions.

The Coalition for the Defence of Human Life praises the compassionate care extended to dying patients by caring doctors and physicians of the palliative care service in the state of Western Australia. It is the Coalition for the Defence of Human Life's understanding that the vast majority of health professionals in this state offer a high standard of care for the dying and that citizens in this state have much to be thankful for if current practices continue to be employed. The coalition urges the government to adequately fund palliative care services especially in regional areas.

We believe that the legalisation of euthanasia and physician-assisted suicide in several countries provides ample evidence that Western Australia should not go down that path. We believe that the legalisation of euthanasia, no matter how prescriptive, cannot prevent euthanasia morphing from terminal cases only to non-terminal cases and from voluntary euthanasia to non-voluntary euthanasia.

The Coalition for the Defence of Human Life urges the Joint Select Committee on End of Life Choices to recommend the government abandon all plans to introduce legislation on euthanasia. Instead we urge the committee to recommend the retention of the current laws, which provide a high level of protection to the elderly, weak and frail.

The CHAIR: Thank you. Did you have a statement, Ms Banks?

Miss BANKS: No, I have no statement to make today.

The CHAIR: In your submission, Mr Randall and Ms Banks, you stated that autonomy, independence or quality of life are subjectively measured and vary greatly. Can you just elaborate on that?

Miss BANKS: I provided the bulk of this submission. The Coalition for the Defence of Human Life firmly believes that dignity is something that is inherent to a human person just by the fact of them being a human person because of who they are. They are a person who is worthy of respect, a person who is worthy of compassion, of love and care. The way a person is treated, especially in terms of end-of-life care, should always reflect the inherent dignity that each and every person has.

I think in society at large there is an alternative view of what makes human beings dignified—these are more subjective categories. There are many people who feel like they might lose their dignity in the face of pain and suffering and especially the loss of autonomy. When people get to the end of life, whether they are just dealing with the frailties that come with old age and need more and more care, or perhaps they are suffering from diseases or illnesses that incapacitate them, they feel like their dignity has been stripped away when they cannot do things for themselves. The Coalition for the Defence of Human Life would say, "No, it is because you have dignity in those situations, we are still going to treat you with care and compassion. It is because you have dignity that we will still feed you and clothe you and wipe your bum and whatever else. It is because you have dignity and a dignity that cannot be taken away that we should be providing good and compassionate care."

Mr RANDALL: If I may add an additional comment to that. The Coalition for the Defence of Human Life believes that the process of dying should never be characterised as undignified. A progressive decline is to be expected and doctors and nurses know how to deal compassionately with it while maintaining the dignity of the person. It is not an undignified thing for a woman to give birth to a

child. It is not undignified for a person to have a colostomy bag, or to be a quadriplegic and need care with daily functions. This does not involve the loss of dignity. It is our belief that if patients are adequately cared for through their dying process, this can be done with a high degree of dignity. What seems to us to be somewhat undignified is the concept of a doctor actually taking the life of that patient.

The CHAIR: You mentioned autonomy. Do you support the principle of autonomy in decision-making?

Miss BANKS: Yes, we do support the principle of autonomy.

The CHAIR: And agree that is a well-established medical principle?

Miss BANKS: Yes. However, we do not believe that this should extend to patients being assisted or helped to end their own life.

Mr RANDALL: For example, if a person is in hospital and has cancer and has been through a couple of rounds of chemotherapy, consulting with their doctor, the doctor says, "We could put you through another regimen but your hair's going to fall out, you're going to be terribly sick and ultimately it will do you no good; you're going to die", the coalition would not argue that that person should be forced to undergo another round of chemo. Of course not. The person has the right to make that decision that ultimately results in the illness or disease that they have extinguishing their life, with care.

Hon ROBIN CHAPPLE: We have obviously heard from a lot of witnesses in palliative care and those sorts of things. There are a couple of practices that are currently considered and that is around terminal sedation or what we refer to as palliative sedation or the dose of double effect. We have heard about different levels of application from different health professionals. When it comes to a patient who is being managed by sedation and the pain cannot be relieved and a dose of morphine or whatever is applied to relieve the suffering that actually eventuates in the death of a person, what is your view there?

Miss BANKS: The Coalition for the Defence of Human Life holds firm that nobody should ever act in a way that directly and intentionally causes a person's death. This we are absolutely firm on. However, as you mentioned, there is the possibility of cases—I believe palliative care specialists could probably explain this a lot better than I can but I hear from them that they say this—in which the reality of drugs such as morphine hastening death and significantly hastening death is not really a clinical reality with the level of palliative care that we have. If that were a reality, the Coalition for the Defence of Human Life, as we have outlined in our submission, believes that administering morphine and other drugs as symptom relief, which also has the effect of contributing to death—I like to be clear that it is contributing—is a contributing factor to death, not the leading cause. So, yes, this is acceptable.

Mr RANDALL: If I could add to that, too, perhaps. The Coalition for the Defence of Human Life also supports Palliative Care Victoria's recommendation that when treating terminally ill patients the level of sedation should be the lowest necessary to provide adequate relief from suffering, and their assertion that continuous sedation from the initiation of therapy is only required in exceptional circumstances. We do appreciate that sometimes alleviating distress and alleviating pain can hasten end of life; Dr Dunjey, when I talked to him, said sometimes by perhaps several hours. Although he also argued that if pain management was administered well, it may actually extend life a little. But when the doctor's intention is to alleviate the pain and not to end the life of the patient, we would consider this good palliative care. When his intention is to give a dose that will kill the patient, then we would consider that euthanasia. We realise it can be a fine line sometimes.

[2.40 pm]

Mr R.R. WHITBY: Mr Randall, would your support of sedation extend to what is known as terminal sedation or palliative sedation where, again, the intention is to relieve pain but it results in a patient being unconscious and dying after that.

Mr RANDALL: Thanks for the question, but can I really say I am not qualified at that level. I am not a GP or a doctor. If the doctor's intention, as I said, is to alleviate the pain but not take the life but the end result is that the patient slips away, then I do not think doctors in that situation would ever be prosecuted or that would be contemplated. I think that is part of good standard palliative care.

Miss BANKS: It is not an ideal, but it is acceptable.

Mr R.R. WHITBY: Can I pick up a couple of points in your submission. You say that euthanasia increases the overall suicide rate, and you also talk about a slippery slope where the categories that assisted dying could be extended to would include the mentally ill. Can you point to, for the committee, the evidence of those comments?

Mr RANDALL: I could talk about a number of different places, if you would like me to do so. Maybe I will skip over Belgium—no, I will not. Belgium legalised euthanasia in 2002 for patients with constant and unbearable physical or mental suffering that cannot be alleviated. In the lead-up to their legislation the euthanasia of children was debated but rejected, yet 12 years later in Belgium euthanasia legislation was enacted to permit lethal injections for terminally ill children of any age. In September of that year the first child died by euthanasia. The number of deaths from euthanasia in Belgium have risen exponentially. In 2000 there were 24. In 2015, 13 years later, there were 2 022, which is an 840 per cent increase. Now Belgian lawmakers are proposing to allow the performance of euthanasia on patients who are unable to express their will, and to oblige doctors to refer patients to other doctors when they do not wish to perform euthanasia. So much for voluntary euthanasia, either for patients or for doctors.

In the Netherlands we see a lot of slip taking place as well. We have now come to the point in the Netherlands that it is proposed that euthanasia should be available to people who are simply tired of life. Legislators in the Netherlands are proposing the completed life bill, which would allow anybody over the age of 75 to be euthanised even if they are healthy.

Mr R.R. WHITBY: The point I was drawing your attention to was about people with a mental illness or mentally ill classification. Is there an example that you can point to there?

Miss BANKS: Yes. There are regular examples from Holland and that. Did you prepare anything?

Mr RANDALL: No. I am not sure exactly where you are going with your question.

Mr R.R. WHITBY: If there is an academic report or any other evidence —

Miss BANKS: I do not have any references of that type on hand. Can we take that as a question on notice, please?

Mr R.R. WHITBY: Sure, you can take it on notice.

Mr RANDALL: I recently read, but I cannot be specific about the absolute details, of an elderly woman with dementia who had indicated that she wished to be euthanised but when the process was going to be implemented actually strenuously objected, and that family members and a doctor held her down while that process was administered. If we could take that on notice, we can come back to you with more information on that, I believe.

The CHAIR: Please do.

Hon COLIN HOLT: In answer to the first part of Mr Whitby's question you specifically quoted a paper around scholars in the US, noting legalising physician-assisted suicide has not led to lower suicide rates but may have in fact increased them.

Miss BANKS: Yes.

Mr RANDALL: That is where I thought she was going to pick up on this question at the beginning. I think that comment is in relation to assisted suicide in Oregon, where over the time that assisted suicide has been legal the number of suicides in Oregon has risen to over 40 per cent higher than the national average, it being a contributing factor. Is that what you were —

Hon COLIN HOLT: I am curious about that evidence. Here is the opportunity to expand on that couple of lines.

Miss BANKS: I do not have anything to add to that specific point that we made in our submission. Can we take it on notice as well, please? I will see if I can dig up a bit more.

Mr RANDALL: We thought it was a credible source when it was quoted.

Miss BANKS: If you would like some more evidence, we can see if we can dig it up for you.

Hon COLIN HOLT: I think it is a really good point. You quoted a paper. We have had 700 submissions, I think, and here is your opportunity to expand on your submission. If you want to expand on that particular point, I am sure we would welcome it.

Mr RANDALL: We will receive reminders on what to expand on?

The CHAIR: Yes, you will.

Mr RANDALL: Otherwise, I might forget.

The CHAIR: Apologies. We will write to you with the specific questions on notice so that you are clear.

I want to touch on the submission as well. You say that pain at the end of life can be adequately dealt with and therefore euthanasia is not necessary. We have had a number of palliative care specialists and I do not think a single one of them has said that palliative care can adequately deal with pain for 100 per cent of patients, even those most vociferously opposed to any kind of voluntary assisted-dying framework. The numbers vary depending on who you speak to, but there certainly has been very consistent evidence that palliative care cannot relieve all suffering. I will give you the example of motor neurone disease, or someone with very intense pain at the end of their life. I invite you to comment on that in relation to your statement in the submission.

Miss BANKS: I am surprised because in my work as a research officer I have seen a lot of statements written by palliative care specialists and I have never seen one statement that would suggest that they do not feel competent to manage all pain. I am surprised by that. That is all I might say. Palliative care specialists would probably be the best ones to answer with those sorts of specific clinical questions.

The CHAIR: They talk about suffering and pain —

Miss BANKS: So you are distinguishing suffering from pain, are you?

The CHAIR: I am not. I am not distinguishing those two, but I would have to say that even the WA palliative care specialists who specialise in this have had enormous improvements in their ability to do that and the numbers are relatively small, but there are those cases where people do die in agony.

Mr RANDALL: If I could make a response, too. In talking with Dr Dunjey, he claimed that none of his patients, even those with cancer, had died in pain. He says that when he has had difficulty dealing adequately with pain relief he sought help from Silver Chain hospice staff, which has always been helpful and resulted in that relief. In his view, refractory pain—intractable pain—is a bit of an indictment on the doctors who are caring for the patient and that more attention ought to be paid to it. Also, Dr David van Gend made the salient point that, even granting that some patients do experience a level of pain, the rejection of euthanasia is not dependent on perfecting palliative care for all patients. In other words, it still does not become a justification. We encounter pain in all aspects of life, but we do not see it as a reason for not living.

[2.50 pm]

Hon ROBIN CHAPPLE: I just want to ask two questions, if I can. I just want to go back to this particular point. We have obviously heard from a lot of people and we have had palliative care practitioners and we have had palliative care specialists before us. An example was given to us the other day that was something we did not realise; we did not actually understand. Even under a fully sedated state patients still do express pain by grimacing, by stiffness of the body and by agitation. Even fully sedated, those expressions were still forthright, so they were not able to control pain. This is palliative care frontline staff. A possible dose of double effect could or would be admitted, administered, to alleviate that, but the upside or downside of that, whichever way you look at it, is that the patient dies.

Mr RANDALL: If I could make a comment there. My wife and I watched our daughter, Sarah, when she had been diagnosed with cancer receiving some sort of a bone tap where they remove tissue and they had placed her under sedation, but it was evident that she was in great pain while they were doing that. Yet, she had no memory of it afterwards. Whether a body shows evidence of writhing in pain, the deeper question is: is the person at any level actually conscious of that at all? I know in the case of many people who have surgery that there are reactions, but there is no conscious memory of that afterwards. I am not sure that the point is entirely valid.

Hon ROBIN CHAPPLE: It is still pain, whether it is remembered or not.

Mr RANDALL: I do not care about my pain that I do remember when I have gone in and had surgery. I may have experienced a lot of pain, but when I have come out, I have remembered none, and I have been very happy to have been anaesthetised. I wonder whether they might not be exhibiting it and yet not personally experiencing it. I am not quite sure how to say that, but if you take my point.

Hon ROBIN CHAPPLE: The second point I want to raise was advance care directives. These are directives where a patient who is fully cognisant of what they are doing signs into the document that given certain sets of circumstances they do not want any further medication, they do not want to be resuscitated, they do not want any further intervention and they just want their pain to be managed. Where do you sit with that, because it is a deliberative act?

Mr RANDALL: It is something I did not consent to deal with in this meeting in terms of the sorts of questions I wanted to answer, but nonetheless if I can offer some comment. I think the decisions that people make when they are young and healthy about what sort of care they would like to receive when they are in some catastrophic situation—the two things can be very, very different when they are actually in that situation. I think that young people frequently think that it would not be possible for them to live after having been in some sort of a catastrophic accident where maybe they end up being a quadriplegic or a paraplegic, and yet when these events happen, they are most delighted to be alive.

I know of the specific case of my father-in-law in Indianapolis, Indiana. We were in the United States at the time, but in a different state, and we received a call that he had been taken to hospital and was critical. He and his wife, my mother-in-law, had both signed advance directives saying they did not want extraordinary care given. I am very thankful that the hospital he went to did not see that. His aorta ruptured and they did their level best to save that man, who apart from that ruptured aorta was in pretty good health and perhaps could have lived for several years later. They flew him by helicopter from that hospital to, I believe, Methodist Hospital, in downtown Indianapolis, where, in spite of trying to get his heart back into action and resuscitate him, they lost him. I was very glad personally, and so was Olive, my mother-in-law, that they took those extraordinary steps. The things that people say when they are healthy, they need to be revised as they get older, because what we find is that life is extraordinarily precious. I am seeing it in myself as I get older that even as my body starts to get frailer in some aspects, I still enjoy life a great deal. I do not know whether that is the coalition's strict view, but that is a personal one.

Miss BANKS: I think it would definitely be consistent with the coalition's view.

The CHAIR: Mr Randall, I want to take you back to your example you gave around futility of medical treatment and the example of the chap who had had two or three rounds of chemo and the doctor says, "I can give you another round. It is probably not going to save your life; it might prolong it for a little while." What about the instance in which the doctor says, "There is a 50 per cent chance that this will work", and the patient then elects not to have that treatment?

Mr RANDALL: I think the patient has a right to make that decision. I think if it had been my daughter, Sarah, when she was 16 and diagnosed with cancer and treated at Charlie Gairdner's, that mum and dad would have said that if it was a 50–50 chance, "Honey, why don't you take it? You might have a full life ahead of you yet." As it turns out, by the way—I kind of left you hanging on that one—she had what was classed as, as I recall, nodular sclerosing Hodgkin's lymphoma. She underwent chemotherapy for a year at Charlie Gairdner's. It practically killed her after every dose. We had people saying, "Don't put her through that sort of treatment." In the end she came out of it, she is married, she has four children and her life is good.

The CHAIR: That is an excellent story.

Mr RANDALL: Yes, it is kind of!

But I think people have the right to make a decision about what they will and will not do.

The CHAIR: Talk about palliative care and access to palliative care and state that there is inequitable access across Australia. Can you just elaborate on that. Where do you think the greatest inequities are?

Miss BANKS: As Palliative Care Australia has indicated, and as referred to in our submission, in regional areas there is a noticeable lack of palliative care. Also, to some extent I am told it is very good across metropolitan Perth as a whole. This document I made reference to was speaking about Australia as a whole. There is a disproportionately large number of services based in the more affluent areas. There are some palliative care services that are not available to people of lower incomes because they are not publicly funded, it is a private system and that causes significant cost to the individual and their families seeking it. This is definitely a concern of the Coalition for the Defence of Human Life. We believe that one of the major reasons that there is a push for euthanasia is that at the moment there is inadequate provision of palliative care.

Mr RANDALL: My little addition to that is when I talked to Lachlan Dunjey—by the way, Lachlan Dunjey is a friend of mine and has been for many, many years—his general assessment was that in the metropolitan area palliative care is fairly good, the standard is fairly high, but where it

needs to be improved is in country regions, and I think that is probably right, but I am the first to admit I am no expert on that at all. I think that this state made a goal of providing, for example, the best palliative care in the world, that it would alleviate a lot of the concerns that people have surrounding euthanasia.

The CHAIR: Thank you both for your evidence today before the committee. A transcript of this hearing will be forwarded to you for correction of minor errors. 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 the 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 your evidence 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. The committee will write to you with the questions taken on notice during the hearing. Thank you both very much for taking the time to appear before us today. It was very helpful.

Mr RANDALL: If I can speak on behalf of Johanna, thank you very much for inviting us to come in. It is deeply appreciated and we are very pleased to learn that you are asking people to come and speak from all different viewpoints. So thank you again. We appreciate it very much.

Miss BANKS: Thank you very much.

Hearing concluded at 3.00 pm

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