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, 9 MARCH 2018

SESSION TWO

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 10.30 am 10:30:51 AM

Reverend PETER ABETZ
WA State Director, Australian Christian Lobby, examined:

The CHAIR: Reverend Abetz, on behalf of the committee, I thank you for agreeing to appear today to provide evidence in relation to the Joint Select Committee on End of Life Choices inquiry. I am Amber-Jade Sanderson, the Chair of the joint select committee. We have Mr Simon Millman, Hon Dr Sally Talbot, Dr Jeannine Purdy, who is our principal researcher, Hon Colin Holt, Hon Nick Goiran, Mr Reece Whitby and Hon Robin Chapple. The purpose of today's hearing is to discuss end-of-life choices in Western Australia and to highlight any gaps that may exist. Your evidence is protected by parliamentary privilege, however, this privilege does not apply to anything you might say outside today's proceeding. 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 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 today?

Rev. ABETZ: Not really, no. I think I know the system reasonably well still.

The CHAIR: Yes, you do! Before we begin with questions, did you want to make a brief opening statement?

Rev. ABETZ: I would like to make a brief opening statement—thanks for that opportunity. For those who are not familiar with the Australian Christian Lobby, it represents about 100 000 supporters in Australia and coming up towards 10 000 in Western Australia. I thought by way of an opening statement, I would like to give a little bit of background to myself in terms of my firsthand knowledge and experience of dealing with end-of-life matters, particularly terminally ill people. Some of you may know that I served as a pastor for 25 years prior to entering Parliament. My first congregation was in Dandenong, Victoria, a very large congregation of about 500 people next door to a large retirement village. In my role as pastor there, I had the opportunity to walk beside people from often the first diagnosis of a terminal illness, walking with them through that journey right to the end of life, doing their funeral and providing pastoral care to the family and so on along the way. I was involved in the mid-80s through the Dandenong ministers fraternal in establishing the Dandenong Palliative Care Service. I was one of the people who made myself available to the palliative care service so that if people being cared for by that service wanted to talk to someone about spiritual things, someone aside from family who was not a medical person, I made myself available for that and, as a result of that, I was able to be with many terminally ill people in their dying days so I was very familiar with the palliative care service that was being provided.

A significant number of people who are diagnosed with a terminal illness have this enormous fear of dying in agony. That was something in pastoral care that just keeps coming up over and over again. One of the things that I was able to do was to assure people that in this day and age of modern medicine, no-one actually needs to die in agony; indeed, in my 25 years as a pastor, and including the time with the palliative care service, I never once saw anyone die in agony. If a person's physical pain started to come to the point at which they were reasonably uncomfortable, often people are quite stoic and think that that is just part of having cancer. But I would say to them, "You don't actually need to tolerate that pain level" and we would get Dr Ruth Redpath, who was the palliative care physician, to visit and usually within eight to 24 hours, the pain was quite under control again

and the person was quite comfortable. It is interesting that current Australian data indicates that no more than two in every 100 palliative care patients end life with moderate or severe pain. For those who do not respond to the normal pain control that is available, there is also the availability of what they call palliative sedation therapy, which provides adequate relief from physical suffering. In my experience, the people who tell stories of having seen a loved one die in agony, when you actually explore that with people, it has invariably been situations where they did not have access to palliative care either because it was not available, they were not even aware that it was possible or because the local GP felt that he could handle it on his own without calling in the expert help of a palliative care physician. It is interesting that in Oregon, where assisted suicide legislation has been in place for a long time, only 28.7 per cent of people who have requested euthanasia actually mentioned physical pain as being one of factors why they wanted euthanasia. Most of the time it is things such as a loss of autonomy and not being able to do things they used to do, but the highest one is being a burden on other people. One of the things we made pretty clear in our submission is that 80 per cent of people want to die peacefully at home, yet in Australia 80 per cent of people are dying in hospitals and nursing homes, which means there is a significant proportion of people whose wish to die peacefully at home is not able to be fulfilled. Obviously, people die from operations and so on so that is not always possible, but there are a lot of people for whom, if adequate palliative care was available, that wish could be fulfilled. In looking at end-of-life choices, we believe that the primary focus needs to be on the provision of palliative care so that everyone who wishes to die peacefully at home is given that opportunity. Sadly, there is a gross under-resourcing throughout the nation of palliative care services. With that, I am happy to throw it open for questions.

The CHAIR: Thank you. Do you think that there are gaps in access to palliative care in Western Australia?

Rev. ABETZ: I believe there are. Obviously, it is simply not possible to have expert palliative care physicians on-site in remote areas and in some of the regional areas. It is a very specialised area of medicine and there is a shortage of palliative care physicians worldwide, I understand. I appreciate that that is a difficulty, but I believe that could be overcome to some extent by enabling doctors in regional areas to access via—I am not sure what the term is—where the GP can talk to a specialist via a video link —

The CHAIR: Telehealth.

[10.40 am]

Rev. ABETZ: That is the term. The GP can talk to a specialist via a video link to get that expert advice so that they can improve the level of care they are able to provide locally. One of the other big issues is that many people in the community are simply not aware of the availability of palliative care. In some settings—I am not sure where it is at at the moment in Western Australia—you can only have palliative care for certain periods of time.

Even if you have a terminal illness and perhaps have a diagnosis of five, six or seven years of life expectancy, it is wise to have palliative care input right at the beginning already. A lot of the issues around end of life are actually about fear. People have all kinds of fears because this is the very first time they are going through that experience. Everybody only gets one lifetime to experience these things and so the uncertainty is huge. To provide not only palliative care but also the pastoral care that tends to come with palliative care can really do so much to ameliorate the emotional suffering that goes with it. Keep in mind that for those who request euthanasia in the places where it is available the biggest issue is those people feeling like a burden. That is always the highest on the list of why people request euthanasia: they feel they are burden to those around them. If we can change that mindset and people do not see themselves as a burden, but, “We value you as a member of

society. Sure enough, you've got a terminal illness, but you are so valuable that we don't want you to jump off now. We want to care for you for as long as you live."

Hon ROBIN CHAPPLE: You talk about people dying in agony and that that can be alleviated by palliative care. We have obviously heard from palliative care specialists and also palliative care frontline providers, and there is an indication that in not all cases can palliative sedation or terminal sedation, whichever one you want to call it, alleviate pain. We had evidence a couple of days ago of a palliative care practitioner describing that even when the person was fully sedated there was a grimacing of the face, stiffening of the limbs and moaning when quite clearly the person was sedated. There is an argument that the person might never actually feel that pain because they go on to die, but there is still that pain threshold. How do you think those cases, which we understand to be between about two and five per cent, can be alleviated?

Rev. ABETZ: That is a fair question. To what extent they are actually feeling that pain, I am certainly no medical expert to comment on. But I think we also need to keep in mind that when people have physician-assisted suicide, euthanasia—whatever term you want to use—between two and four per cent have a very bad reaction. Some people go into having fits; some people end up in significant pain as they go through that process. The most disturbing one that I read about was a man in Oregon who ended up having fits and things and then ended up waking up two days later. He went on to live for another six weeks apparently. Even with physician-assisted suicide it is not always smooth sailing, and that has certainly been the experience in Oregon and the Netherlands. I have some figures here somewhere. I think in the Netherlands they say it is two per cent and in Oregon I think it is four per cent, but I would have to double-check that.

Hon ROBIN CHAPPLE: I think we have heard ourselves a number of variations on that. We tele-linked through to Dignitas yesterday, and they were saying in over 2 500 they have never had a situation like that. I think from jurisdiction to jurisdiction there are some issues, and I agree with you. But I am really coming back to this notion that palliative care is the panacea. I really support palliative care. Do not get me wrong; I think it is a marvellous system that should be expanded, but quite clearly currently it cannot deal with certain cases. So if we are to provide a good end of life, how do we need to resolve those issues? I am seeking your input.

Rev. ABETZ: I think we live in a world where nothing is perfect and so there will be some situations that are very difficult, but I think to make legislation on the basis of exceptional cases is never good legislation. I think that as general kind of rule, as a former legislator myself, that is not a good way to go, because you need to make the laws to protect the bulk of the people and on the edges there are always things that legislation cannot perhaps fully cater for, such as the needs of some individuals or their perceived needs. But keep in mind that even with physician-assisted suicide there are significant issues around that as well in terms of people suffering as they go through that process.

Hon ROBIN CHAPPLE: Reverend Abetz, quite clearly you represent a Christian lobby and I understand the moral position taken by the Christian lobby, the Jewish lobby, Islamic, whatever, around this. I would hope there is no compunction, if legislation is to be introduced, that people of faith need to be involved in the process. Does that relieve you in some way or do you think that your convention has the right to determine the outcome for people who are not of that conviction?

Rev. ABETZ: You are certainly right about the conviction side, I do not dispute that at all, but I think if you look at it simply from an objective, rational sort of perspective, what has happened in say the Netherlands or in Oregon, what we see happening there is that originally there were very tight boundaries around euthanasia or physician-assisted suicide and so on, and those guidelines, we have seen in other jurisdictions as well, they keep being moved. Even if the legislation has not

changed, in actual practice they are violated. I have a little quote here from *The New York Times* from back in 1996. The person wrote —

> The Netherlands has moved from assisted suicide to euthanasia, from euthanasia for people who are terminally ill to euthanasia for those who are chronically ill, from euthanasia for physical illness to euthanasia for physical distress, and from voluntary euthanasia to involuntary euthanasia.

The official Dutch annual report on euthanasia indicates that they are aware of at least 1 000 cases since euthanasia was legalised in the Netherlands in which there has been involuntary euthanasia. I think one of the real problems with euthanasia is that it changes the doctor–patient relationship. In our submission we make mention of several people in the jurisdiction where euthanasia is allowed who went to hospital because they had a terminal condition and the doctors were trying to decide whether it was worth giving this treatment to this person who was not in a position to respond. It was only because her husband was there and able to say, "Her life is worth sustaining. She has an episode several times a year for which she needs emergency medical care." They were out of area. The hospital did not recognise them as regulars. They were talking about letting her die, and she was in a state in which she could hear but not communicate. It took her husband to put his foot down and demand that they continue to provide the treatment that was needed. We give that example in our submission. They are the kinds of issues that are very real. In Belgium, I think last year, a transgender person who was not happy with their sex change operation and who was in their mid-40s—physically no pain, no terminal illness—was allowed to be euthanased.

There is this shifting across to basically anybody can choose to be euthanased, just about. That drift, over time, we see as a really serious issue. I think with the House of Lords' inquiry into euthanasia, they came to the conclusion that it is simply not possible to put sufficient legal safeguards into the legislation to protect the vulnerable.

[10.50 am]

Hon ROBIN CHAPPLE: In terms of your earlier comment about prognoses and doctors making decisions, do we not have that currently when it comes to advance health directives or, indeed, the notation of "Do not resuscitate"? Are they a problem as well?

Rev. ABETZ: No, I do not have an issue with the advance health directives. I do not believe that the Australian Christian Lobby as a whole would have an issue with that because the issue is one of, "Do we allow nature to take its course or are we actively killing someone?" I believe there is a very radical difference between the two. I can give a personal example —

Hon ROBIN CHAPPLE: I think you mentioned before that doctors were making decisions to not treat patients and were therefore causing their death, whereas an advance health directive asks a doctor to not treat them, thereby causing their death. Also, "Do not resuscitate" is a directive that, "When I get to this state, I don't want to be resuscitated." I am struggling with that differential.

Rev. ABETZ: I think there is a radical difference between suicide and allowing nature to take its course. I can give the example of my own late father. He had a terminal illness and he probably could have lived a little bit longer if he had gone in and out of hospital umpteen times, but he said, "Look, I'd rather just die at home. Just don't take me back and forth to hospital." We as a family looked after him and he died peacefully at home. I respect that decision to let nature take its course; I see that very differently from asking the doctor to come and give my father an injection to end his life. I see a very significant difference there.

The CHAIR: Do you consider an individual who withdraws from life-sustaining medical treatment as committing suicide?

Rev. ABETZ: If an insulin-dependent diabetic, for example, were to decide, "Look, I'm not going to take my insulin anymore", I would see that as his life being quite sustainable.

The CHAIR: I actually want to ask you about advance health directives. Are they, in your view, commonly understood and used in the community?

Rev. ABETZ: I think there is still a lot of ignorance around that. I have a sister in Tasmania who has been in healthcare as a nurse all her working life. When she retired she actually went around on a voluntary basis to the nursing homes in her area to assist the residents to make use of that facility. I do not have any indication to what extent that is known here in Western Australia, but my guess would be only a very tiny proportion of the community actually avail themselves of advance health directives.

The CHAIR: Do you have a view as to why it is so small, the take up?

Rev. ABETZ: I think our culture does not want to talk about death. With so many people dying in hospitals and nursing homes, it is removed from the common life experience, whereas perhaps 50 or 60 years ago, I am not sure what it was like, but my guess is that a lot more people were actually exposed to seeing auntie or grandma or whoever passing away, so death was more part of life, if I can put it that way. A lot of people do not even want to face the reality. When I was working as a pastor with the palliative care situation, all too often there were people who were clearly dying but they did not want to face the reality of their mortality, which made it very difficult for the families to deal with, because the person refused to acknowledge that they were dying, so any attempt to talk about what they wanted for a funeral or whatever became a no-go zone, which became very difficult. It was one of my tasks as a pastor to try to break through those barriers and get people to talk about those things. Usually when people do, they are actually very glad that they have. It is often just the fear of the unknown that hinders that.

Mr S.A. MILLMAN: Reverend, you referred to the *New York Times* article before. Is it possible for us to get to the citation for that? Was that an op-ed piece in the *New York Times*?

Rev. ABETZ: It was from July 1996. I am sure we can dig that out for you. Perhaps I can take that on notice?

Mr S.A. MILLMAN: Yes, thanks very much.

The CHAIR: I just want to draw your attention to a comment you made earlier about the House of Lords' report, which found that it is impossible to put enough safeguards in. The Canadian courts found that it was possible to protect vulnerable people and therefore rejected the challenge to the assisted dying laws. Do you have a comment on that?

Rev. ABETZ: If you look at the history of what has happened in the Netherlands, I guess I am a little closer to the Netherlands situation than the Oregon one, because I am married to a Dutch girl and we visit the Netherlands reasonably regularly to visit relatives of hers. The fact is that in the Netherlands you hear elderly people expressing the fear about being worried about being put down without their agreement. The fact that people talk about that is a real concern. People should not have to worry about that in their old age, yet that is a reality for a lot of senior Dutch people. I am told that there is actually a bit of a growing industry of Dutch people choosing to move to Germany for aged care because apparently Germany does not have euthanasia laws at this point in time, so they feel safer there. I think that is deplorable.

The CHAIR: One of our terms of reference is to look at potential legal changes that are required. Do you think doctors are protected under the current law with regard to terminal sedation, as you mentioned, and their reliance upon the doctrine of double effect?

Rev. ABETZ: I am not a lawyer so I am not sure exactly how the law stands on that, but if legal experts say there is a need for strengthening the protections for doctors then I believe that should be done. I could be wrong, but it is my understanding that it is a long-established medical principle that if the motivation or reason for giving the medication is to alleviate pain, that is perfectly acceptable, whereas if the purpose of administering the medication is to end a person's life, that is crossing that line. Somebody who has more legal knowledge than me may be better equipped to answer that one, but from an ethical perspective, I think it was Thomas Aquinas who made the distinction between giving medication to relieve suffering; that was acceptable, even if it is known to shorten life, for the sake of reducing suffering. Ethically, there is no issue from my perspective in providing medication that reduces suffering but, as a side-effect, also shortens life. I do not have an issue with that.

Hon NICK GOIRAN: Just on the Canadian issue—you may need to take this on notice—it was put to you that in Canada there is a view by the judiciary that it is possible to legislate safeguards and that that is different to the British system, where the House of Lords took a different view. Have you had the opportunity to research the Canadian system and to identify if there has been any failure of the safeguards in Canada?

[11.00 am]

Rev. ABETZ: I have not done any research on that, but I could certainly look into it and take that on notice if that would be helpful to the committee.

Hon NICK GOIRAN: Sure.

The CHAIR: Sure. Was there anything else you wanted to add, Mr Abetz?

Rev. ABETZ: I would just like to say that I think one of the key points I would like to make is that if we move towards legalising assisted suicide, it really represents not just a slight shift in the way we view life but actually it is a huge paradigm shift because western society has been based on the view that every human life has inherent value—often referred to as the sanctity of human life—as an absolute objective kind of fact. That is what our system has been based on. There have certainly been other cultures where they do not have that approach. For example in India, you would probably know, when a man died the woman was thrown onto the funeral pyre because she had no value apart from her husband. To us that is totally repugnant, because her husband has died but she still has inherent value, so the British put a stop to that in India. If we allow assisted suicide, we are actually moving away from that view of the sanctity of human life to a very subjective view of the value of life depends on to what extent life is valuable. That is a very subjective way of dealing with human life. I think that standard of where does the quality of life diminish to the point where it is not worth supporting anymore is going to be a very easily eroded standard. We have seen that in the Netherlands. We have seen it in Oregon. Incidentally, just in the last few weeks in Oregon they have passed legislation which allows doctors or medical professionals to withdraw water and food without the consent of a patient if they believe that is appropriate. Under their advance health directive legislation, a person could actually say, "If I suffer dementia or Alzheimer's to whatever degree, then I want food and water withdrawn and I can be starved to death." Their law allowed that. Now, it has shifted to the point where the doctors can make that decision for a person without their consent. Again, it is an indication of just how quickly those boundaries can change.

Hon COLIN HOLT: Have you got any references for that? Where did you come across that?

Rev. ABETZ: I just came across it the other day. I will take that on notice. I can certainly provide the reference for you. It was in the media.

The CHAIR: Is it not also true that futility of medical treatment also does not require consent? So a medical professional deem a treatment futile and not provide that to the patient, despite the patient wanting it. That does not require consent either.

Rev. ABETZ: That would be my understanding. For example, if a person is suffering a form of cancer for which there is no known chemotherapy that helps but the patient absolutely insists, "I want chemotherapy", I believe the doctor has an ethical responsibility to say, "Look, sorry; there is no chemotherapy that can help this particular cancer, so we are not going to give that to you."

Hon NICK GOIRAN: Mr Abetz, though, isn't it the case that that is not the consent of the patient; that is the consent of the doctor. Futility is, with respect, where the doctor has determined whether the treatment is going to be futile or not. The doctor may well say that the chemotherapy is not worthwhile but the patient can go to another doctor and consent to the treatment from that doctor. With all due respect to the question that has been put, it seems remarkable that you could conflate consent of a doctor and consent of a patient.

Rev. ABETZ: Assisted suicide is basically about a person being assisted to commit suicide. So the question is: is it appropriate to assist someone to end their life earlier than what it would if nature took its course? I think that is a very radical shift from where we have been as a society.

Hon ROBIN CHAPPLE: During the passage of my last legislation, a former Premier said that he and doctors made a decision about their relatives—about treatment and those sorts of things. What is your view of others making a determination about the life of a relative?

Rev. ABETZ: If there is no advance healthcare directive, then those who are next of kin or have enduring power of attorney—whatever the technical terms are for that authority—would have to make those decisions. Somebody has to make the decisions. Again, somebody who is better versed in the law could answer that.

Hon ROBIN CHAPPLE: In a case like that where they agree with the doctor that medication that may affect the end of life be administered, is that permissible?

Rev. ABETZ: I am not 100 per cent sure I understand. Take the example of somebody who is in the very end stages of Alzheimer's and does not know anything that is going on around about them. They now say get pneumonia and the doctor asks the family, "Do you want us to treat him with antibiotics?" That is a question that the family would need to answer, and I respect the right for the family to make that decision as to whether to let nature take its course, or to try and intervene once more in that particular person's life.

Hon ROBIN CHAPPLE: I think the commentary on this particular issue on the ABC was that it was much more proactive than that.

Rev. ABETZ: Again, if the motivation was to end life—if that is the purpose of administering whatever medication it is—to me, under our current legal system that would actually be contrary to what is allowed. If the purpose of administering the medication was to make the person more comfortable and a side effect would be that their life might be shortened, then that is perfectly acceptable. That would be my understanding.

Just one quick comment I would still like to make is that I noticed in the evidence that the police union gave the other day —

The CHAIR: They actually have not given evidence to the committee. It was in the media.

Rev. ABETZ: It was in the paper only, was it?

Hon COLIN HOLT: Just commentary.

Rev. ABETZ: Right; okay. I would just like to comment on what was in *The West Australian* then, if I might.

The CHAIR: Sure.

Rev. ABETZ: Apparently, 240-odd people have committed suicide who were terminally ill since 2012, I think it was.

Hon ROBIN CHAPPLE: That is known figures.

Rev. ABETZ: Yes. My comment on that would be, I fully sympathise with the police at having to go to places where there is, for want of a better word, a messy suicide—how traumatic that is, not just for the police, but also for family members and so on. But what I would want to say to that is, simply offering those people a less messy suicide—I think we can do much, much better as a community than just to offer a less messy suicide. I believe that with proper palliative care and support services, very, very few of those people would have opted for suicide. I think it is actually a reflection of the inadequacy of palliative care services, the fact there are so many that apparently commit suicide. I think we really need to step up our palliative care and support services to prevent people from wanting to take that exit option.

The CHAIR: Reverend Abetz, thank you for your evidence before the committee today. 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 via 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 of evidence. Thank you very much for taking the time. We will also write to you with questions taken on notice during the hearing.

Hearing concluded at 11.10 am

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