

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
TUESDAY, 1 MAY 2018**

SESSION SIX

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**

<014> U/H [1.55.27 pm](#)

Hearing commenced at 1.55 pm

Mr PAUL BYL

Private citizen, examined:

Mrs LISA JAYNE BYL

Private citizen, examined:

The CHAIR: 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. We have Mr Simon Millman; Hon Dr Sally Talbot, who will join us shortly; Mr John McGrath; Dr Jeannine Purdy; Hon Colin Holt; Hon Nick Goiran; Mr Reece Whitby and Hon Robin Chapple.

The purpose of today's hearing is to examine the adequacy of the existing laws and resources in relation to end-of-life choices from your perspective as a member of the community willing to share your personal experience. 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 does not apply to anything that you might say outside today's hearing. 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 either of you have any questions about your appearance today?

The WITNESSES: No.

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

Mr BYL: Yes, I would like to.

The CHAIR: Please do.

Mr BYL: Thank you for inviting us to this hearing. Parliament has given you an important task—one that will impact people's lives. God also has given you an important task. He wants the world, and in this context WA, to be governed by laws and statutes in order that the lawlessness of men be restrained and that everything be conducted among them in good order. We acknowledge that it is not an easy task you have been given and that you would feel pressures from many sides. It is our prayer that you give good leadership on this matter of end-of-life choices. The high level incomplete spinal cord injury I sustained 21-plus years ago has had a profound effect on the life of my wife as well as myself. In an instant our lives were changed forever. For me it meant a loss of independence in many areas of daily living, requiring assistance with simple tasks of personal care, including emptying my bladder and bowel. It is especially the emptying of my bowels that is the most unpleasant. It is unpleasant for me and unpleasant for whoever is helping me. It is one thing as a child to require assistance when toileting; it is quite another when you are an adult with a whole life ahead of you. It is also not something that will get better over time.

The strain of attending to all my personal care and showering is too great for my wife. As a consequence, we employ carers to help with this. Over the years I have had a number of carers and I have taken the opportunity from time to time to ask these ladies whether or not they would support euthanasia for those who are ill or do not have quality of life. Some have answered in the

affirmative—that yes, they would support it for those who are sane and do not have quality of life. I then asked them what they would think if I were to say that tomorrow I would like to be killed. Interestingly, they exclaimed, “But you’ve got a lovely wife and a beautiful son.” My response then is, “Exactly. But having a lovely wife and a beautiful son does not cause my bladder, bowels and other functions to function normally. They do not cause the spells of pain and discomfort to turn into pleasurable sensations. Further, I feel a burden on them. Because of me, they cannot go out and about freely like other able-bodied people. My wife cannot experience intimate moments as other females in other relationships can. Further, as I age I will need increasing assistance. As for our son, he cannot play cricket, soccer, or football with me, fly a kite or surf like other boys can with their dads. Not only is my quality of life diminished—so is theirs.” To this reply, my carers do not have a good answer.

[2.00 pm]

So we get to an important question. If you are going to recommend to Parliament that euthanasia be legalised, at what point do you make it illegal? At what point will you say to someone, “No, you must continue living”? And why must—I emphasise the “must”—they continue living? It is cold comfort to someone when they are told, “Cheer up. Look at so-and-so. There is always someone else in a worse position.” It is only logical that if euthanasia is legalised with, of course, safeguards in place, that these safeguards will be challenged. Equality and anti-discrimination demand that they be challenged. Euthanasia with safeguards means a select few will be allowed to die. They are on the right side of the barrier, so to speak. But what are you going to say to the guy on the other side of the barrier or, in fact, even up against it? Are you going to say, “Sorry, mate. Your life isn’t tough enough. You’re not enough of a burden. You’ll have to keep living”?

Euthanasia concerns me greatly, especially because I have a disability. If legalised, people like myself will be vulnerable, especially as time goes on. People with disabilities or incurable illnesses will have to choose whether or not they want to be a burden on other people. Euthanasia will become normalised in our society and people like myself would be conditioned and pushed towards it. People who do not want to die will die. An ethical threshold is crossed if we legalise euthanasia. There will be people who society will say, “Their lives are worth living.” And there will be those who society will believe are better off dead. Allowing people to legally end their life has consequences for our entire society. As stated in another submission, it is either God’s way or confusion and chaos. Either society recognises that all life is valuable or we will not be able to find a good, fixed, unchallengeable reason to stop anyone from committing suicide.

In summary, euthanasia is both unnecessary and unsafe. If legalised, it will reduce the choice of care and support of those in need. We already have the answer to end-of-life choices and suffering, and that is palliative care. But it needs more promotion and better funding. We urge the committee to take the opportunity to inform and educate Parliament and the public of the benefits of palliative care and why euthanasia is an unnecessary and dangerous option, undermining society’s responsibility to protect its most vulnerable members. Thank you.

The CHAIR: Thank you very much, Mr Byl.

Hon ROBIN CHAPPLE: Thank you for your presentation and, both of you, thank you for attending. You talk about safeguards in what you have just said. Do you think there are safeguards or do you think there are not? Are there safeguards available to protect people who are vulnerable if such legislation were to be introduced? If there are not, what do you think may need to be in place to ensure those safeguards? We have obviously had a number of people who have disabilities in here and we have heard that, obviously, people in your situation can feel vulnerable and threatened by end-of-life choices, which are dealing with that. Is there a safeguard or is there no safeguard?

Mr BYL: You can put safeguards in place. You can put laws in place that will say, “You have to meet these conditions and then you can be euthanased.” But those safeguards will be changed. You cannot legislate that safeguards cannot change. Over time, they will change.

Hon ROBIN CHAPPLE: I hear your commentary. Is there any particular evidence that they will change in a negative or a positive way? There seems to be an argument that is being presented that if legislation is introduced, it will change. It can change in many ways. It can become more restrictive. It could become more expensive. I am trying to work out if there is evidence that it will change.

Mr BYL: I understand that in Canada laws are already being challenged, where euthanasia is legalised. People are saying, “I’m not allowed to die and I want to die.”

Hon ROBIN CHAPPLE: Do you think that an end-of-life choice that involves assisted dying can be changed positively or negatively? I have lost my train of thought. I do apologise.

The CHAIR: Mr Byl, I will pose a question. We have had quite a lot of evidence from people, both health professionals and people who have watched loved ones die in palliative care in what are quite harrowing and horrific circumstances. Despite the very best medical attention and tools available to those palliative care workers, they were not able to relieve very intense suffering and pain at the end of life. That is quite a compelling case for people who do support voluntary assisted dying—palliative care specialists admit that they cannot help everyone—those people who have an inevitable end-of-life very near should have access to a more peaceful exit at a time more of their choosing. Do you have a comment on that and what could we do for those people?

Mr BYL: I am not sure that there are no choices available for them in terms of pain relief to make themselves more comfortable. From what I have read from other palliative care doctors, they say there is assistance available for these people.

The CHAIR: Palliative care specialists will themselves openly say that they cannot help everyone. At least—the figures that we have been presented with—two per cent of people cannot be assisted.

Mr BYL: But we would also say that it is God who gives life and it is God who takes life. We are not allowed to end our lives deliberately prematurely.

Mr J.E. McGRATH: Thanks, Mr Byl. When you talk about your situation, obviously you have a very caring family. Those people who spoke to you when you ask them—those carers—they said you have a lovely wife. That is something that is very special. A lot of people in your position have families who want them to stay around. Whatever the inconvenience, they want you around because you are a loved one. You talk about people being coerced or people’s choice—you look at someone like Stephen Hawking. He did not want to end his life and he stayed around for a long time. There would be a lot of people out there with disabilities who would be in the same position. Obviously no-one knows what it is like to be in that position until you are, but a lot of people become determined and they live their life the best they can. The community and governments now support people with disabilities a lot more than they once did. Do you think there would still be pressure on people with a disability if the option was given, or do you think that most people would still want to stay alive with their families, even under those difficulties?

[2.10 pm]

Mr BYL: I think the pressure would increase on those people to be killed—for euthanasia.

Mr J.E. McGRATH: Pressure from where?

Mr BYL: Society in general. This is looking down the track—years down the track when it becomes normalised and euthanasia is a normal thing; it is nothing special; it is a normal thing you can have. There will be pressure on people. They will see themselves as being a burden. Also, it could be a

young child and its parents. Somebody with a serious disability is a lot of work for their family members. Over time that person might realise and think, “Well, I am being such a big burden on them.”

Mr J.E. McGRATH: Most people would not agree with that principle, I am sure. Most people in society would not agree with that with children.

Mr BYL: Would or would not?

Mr J.E. McGRATH: Would not. Most people would not agree with that—that children could be euthanased. I think that in some jurisdictions, it is not allowed anyway. I was just getting back to the point that we are told by a lot of people who come here, especially medical people, that the right to live is so powerful in most people. Not many people want to end their life. The will to live is a very powerful thing. I would think that you would have it.

Mr BYL: Yes, but I have met other people who do not want to live anymore.

Mr J.E. McGRATH: In what circumstances would they be in—those people?

Mr BYL: They have suffered a spinal cord injury and they think, “If this is what my life is going to be about, I’m not interested.”

Mr J.E. McGRATH: Once again, that would have to be their choice. If you put the proper safeguards in place, as has happened in Victoria, those people might be talked out of it because before they went that far, they would be given some help and assistance from care groups or palliative care groups. They can be convinced that: “You might think you want to do that, but you should not. You have a lot of life ahead of you.” That is what a lot of people are saying to us—that is what we as a society should be doing for people, whether or not euthanasia comes in or not. It is very important that people get that support when they are feeling down. Do you agree?

Mr BYL: To give them support? Yes. But I would not say to them, “There is an option for you and that is euthanasia.” That is not an option. They need encouragement and to allow them to be euthanased is not giving them encouragement.

<015> I/A [2:14:10 PM](#)

Mr J.E. McGRATH: That is a good point that you make. A lot of people have made that point to us—that physicians or GPs should not be encouraging people in any way at all; it should be the person’s decision if they really come to that point in their life or they are close to passing. I do not think society would want GPs out there advertising that you can do this or telling their patients that this is an option for them.

Mrs BYL: I was not going to speak up, but I am just wondering: are you only dealing with cases where somebody has the mental capacity to make that decision themselves?

Mr J.E. McGRATH: Yes.

Mrs BYL: When my husband had his accident, at the time they did not know if he would survive, and I know plenty more.

Mr J.E. McGRATH: You were married at the time?

Mrs BYL: Yes.

Mr J.E. McGRATH: You would obviously have been consulted by the specialist after the accident?

Mrs BYL: Yes.

Mr J.E. McGRATH: Was anything put to you about your husband’s future?

Mrs BYL: They said, “We just don’t know.” He was in a very bad position, and thankfully the Lord blessed the treatment and he is where he is now.

Mr J.E. McGRATH: For you, being in that position, that was a great outcome, because at least you were in a position where the result might not have been good, but your husband has survived.

Mrs BYL: Yes, and that is why I asked whether it is only when people are in that state. He was in a coma for a while. What happens if that had lasted for 10 years? Do you then say, “Well, let’s change our rules so the family can decide for him”? That is not leaving the answer to the Lord. When he had his accident and when my brother was burnt, we said, “We’ll leave it to the Lord.”

Hon COLIN HOLT: I just want to go back to what Hon Robin Chapple suggested. I think what he was asking was around your fear that once we have a legalised framework for voluntary assisted dying, it will be the thin end of the wedge and could potentially be expanded into the future. Is that your greatest fear in terms of the legalisation of voluntary assisted dying?

Mr BYL: I do not know if it would be the greatest.

Hon COLIN HOLT: So it is one of your concerns?

Mr BYL: It would be one, yes.

Hon COLIN HOLT: If legislation gets debated and passed in Parliament, any changes to the legislation will have to go through the same sort of process into the future, and who knows what that could hold, because it will be a future Parliament and future MPs who might have a whole range of different opinions. But what we are dealing with at the moment is the debate that we are having right now, and, if the legislation is to come in, the safeguards that can potentially ameliorate the concerns of the vulnerable about how it can change in the future. It is something we all need to consider.

Mr BYL: There are plenty of non-religious people as well who point out the dangers of euthanasia. There are plenty of people with serious disabilities who speak and warn about legalising euthanasia.

The CHAIR: I want to put this in perhaps a slightly different context—Mrs Byl really touched on this in her comments—around futility of medical treatment and current options available. There is a scenario now where individuals can withdraw from medical treatment and next of kin can withdraw relatives from medical treatment. The example that you gave was of somebody on life support. That can currently be withdrawn, and people can, and do, elect to withdraw from any food or water to hasten their end. Those are options available to people now. Do you have an opinion on those two options?

Mr BYL: That is still very different from euthanasia. With euthanasia, you are actually giving something to deliberately end that person’s life.

The CHAIR: One of the quite common practices in palliative care that we have been hearing a lot about is terminal sedation. There is evidence that when somebody is put into a deep sedative state at the very end of their life to manage their pain, it can bring forward their death. That is a common practice now. Do you have a view on that practice?

Mr BYL: Not really, no. That would not be a concern for me.

[2.20 pm]

Hon ROBIN CHAPPLE: I remember what it was I was trying to remember before. I am old. These people know me! I tend to forget things! You mentioned in your introduction the issue that if you create a specific time or condition when somebody can access voluntary assisted dying, you could actually be denying access to others. I think what you were talking about there was this cut-off point

between who could access and who could not. I understand your position and your views more generally, but that was an area of concern. Do you want to expand on that at all? If you do not want to expand on it, what do you think may be a cut-off point? Quite clearly, you were saying that certain people at a certain point could not access it, and therefore it was discriminatory. Do you want to give me some thoughts on that?

Mr BYL: I am not sure what is not clear enough about that point.

Hon ROBIN CHAPPLE: I think you were saying, if I have it right, that if legislation was brought in and the person who was diagnosed as being terminally ill now had six months to live, that would be denying people who had nine months to live—that they would not fit within the criteria. That is what I interpreted you to mean. I am trying to work through that.

Mr BYL: That is an example of why the laws will change. A person with nine months to live will say, “Well, why can’t I die now?”

Hon ROBIN CHAPPLE: So that was the argument for —

Mr BYL: They will argue on the basis of equality and antidiscrimination, and how will you be able to say no?

Hon ROBIN CHAPPLE: My response would be that any legislation that goes through any Parliament anywhere becomes legislation and you cannot just change it at will. But I take your point.

Hon NICK GOIRAN: I have thought long and hard whether to ask this question. I have lost count of how many hearings we have been in, but it is probably the second hearing I have been in where I am actually uncomfortable with the existence of this committee. I wonder: how does it feel for a person with a disability to be sitting where you are? There was a gentleman earlier today who was available via Skype; he was not sitting in front of us. How does it feel for a person living with a disability—I note that this is 22 years—to have a committee of the Parliament discussing and debating the merits of your condition and whether or not you would qualify to access assisted suicide? I would be interested in your thoughts on that.

Mr BYL: We are thankful that we can speak to the committee. At the same time, I think it is a sad development that we are even having that debate. It is all very polite, but, in the end, if euthanasia is legalised, it does not matter how polite it is or how polite the debate or the discussions were. If euthanasia is legalised, people are going to die down the track. People who did not want to die will die.

Hon NICK GOIRAN: Mrs Byl, you have also been one of the very polite people in the room and have not said too much. I am just interested if you could share with us your experience as a carer for, as I note here, 22 years. If you want to perhaps put it in writing at another time that is more comfortable and convenient to you, that would also be fine.

Mrs BYL: I guess I would not have a real lot to say except that 22 years, yes, it is full of ups and downs. Some days are better than others; it is not easy. Some of you are just going to think, “Oh, yes, here goes another one going on about God”, but it is God who gets me through and that is the only way. You hear a lot of talk about quality of life. I just think, boohoo to that term, “quality of life”; I hate that term. I think quality of life is just totally irrelevant. God gives life, God takes life, and in between we are all worth the same. If somebody costs more to society than what they can give back in terms of monetary value, whoopee-doo. They should never, ever come into the question. I think we put in our submission that we leave things with the Lord, and that is not easy. I saw my dad die, and it is not easy, but we go on in faith, and as Christians we know that our life here on this earth is not what we are here for. We are passing through. We have a task here to live to God’s

honour and glory and we look forward to Christ's return to the new heaven and the new earth, where there will be no more disability. That is about all I can say.

Hon ROBIN CHAPPLE: Thank you.

The CHAIR: Thank you very much, Mr and Mrs Byl, for appearing today and answering some very personal questions. It is very difficult for a lot of people to come and give evidence and the committee really appreciates people's willingness to come and share your experiences and your views, and we respect those across the board. It is very, very valuable that we hear from you, so thank you very much.

I am going to just read the closing statement now to officially conclude the hearing. A transcript of this hearing will be forwarded to you for correction of transcribing 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. Again, thank you both very much for taking the time to come and speak to us today.

Hearing concluded at 2.28 pm
