

# **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, 5 APRIL 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 11.06 am****Mrs ESTHER HUMBLE****Private Citizen, examined:****Mr MATTHEW HUMBLE****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; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; and Hon Robin Chapple. This is a closed hearing and Hansard will be making a transcript of today's session. The transcript will not be publicly available unless the committee or the Legislative Assembly resolves to authorise its release. It is important that you understand that any deliberate misleading of the 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. Could you please introduce yourselves, for the record.

**Mrs HUMBLE:** Hello, everyone, and thank you for this opportunity. My name is Esther Humble and this is my husband, Matthew Humble. I have asked him to come along because I am nine months pregnant, just in case I need his assistance. Thank you for this opportunity today. I come here to talk about experiences. I have worked in the field of disability for over 10 years.

**The CHAIR:** Do you have any questions about your appearance today?

**Mrs HUMBLE:** No, I do not.

**The CHAIR:** Did you want to make an opening statement?

**Mrs HUMBLE:** Yes, I would like to.

**The CHAIR:** Go ahead.

**Mrs HUMBLE:** Thank you once again for this opportunity. I have worked with people with disability for over a decade and I have had personal and professional experiences with people with terminal illnesses. I would like to share my grave concerns regarding new legislation involving voluntary assisted dying, such as what has just recently passed in Victoria.

My first concern is that people will be killed wrongly, despite whatever safeguards are put in place at the beginning of such legislation, and in particular I feel that people with disability will be particularly vulnerable, for a few reasons. One is that they already experience a lot of difficulty in accessing basic healthcare and community services. Should it be that euthanasia is an easier option for them to access than basic health care, that would be very, very wrong. That is a concern by disability advocates such as Craig Wallace, who says that until people with disability are able to access the same level of community services and health care and have access to the same choices of health care, then euthanasia is a poor choice that should not be offered. Would it be right to have easier access to euthanasia than to proper dental care? That would be wrong, and also these things put people with disability at higher risk of experiencing suffering considered to be intolerable. It is how society relates to them. Also, we do know that people with disability experience high levels of abuse and all these factors can lead to them becoming more vulnerable, I would say, to choosing an

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option which might be because there are limited options rather than because that is the best option for them.

Also, while currently in Victoria the legislation specifies that nobody other than the patient himself or herself can access voluntary assisted dying, I would say that if we went down this path, this would likely change because if euthanasia is generally a good choice, then really it should be available for all people and not just people who can communicate and people who can speak for themselves. As a speech pathologist working with people with disability, often there is needed to be somebody to speak for them if they have communication problems, to be their advocate, so I would say that down the track, logically, legislation such as the Victorian one would probably be expanded to include a support person and someone who can express the person's wishes, but then of course there is the complicating factor that there will be error. Already in society people with disability are often thought to have a poorer quality of life than they feel they have, so perceptions of other people are likely to affect how they would be treated. Again, I see vulnerability here.

[11.10 am]

My second main concern is that health professionals, particularly physicians, in this instance will be encouraged to operate outside their scope of expertise. Looking at the Victorian bill, where people with disability and mental health are not exempt from the bill, the two doctors involved in the assessment are not, to my knowledge, required to have any experience in the areas of disability or mental health, yet they are supposed to be able to assess and ascertain that the person understands the situation, that they have not been coerced and that they have decision-making capacity. For me, as a speech pathologist who assesses language comprehension, I find this astounding. Also, they are expected to share the range of palliative care options that are available, but again I note that palliative care is not directly involved in the assessment. I would question how much a general physician would know about all the palliative care treatments that are available, knowing that it is quite complex myself.

I read some of the submissions from palliative care that came in. It certainly is a very complex issue and, as they say, each case is very individual. For me, for a general physician to be able to cover all these areas would be outside of their area of expertise. I do not believe the solution would be to involve more health professionals, because no health professional is qualified or trained to ascertain certain things that would be required of them—whether someone has been coerced or not. Also, it puts health professionals into a position in which they are encouraged to think about whether it is better for a person to be dead than to be alive, and I think that this is dangerous. In Belgium there were physician-assisted deaths, which I am sure you have heard of before, that happened without explicit patient request. I have a statistic here that in 17 per cent of cases this was because the physician thought that the decision for dying was in the patient's best interest and they did not discuss it with them. So, we have health professionals who are beginning to think that they know more than the patient with regard to whether the patient should live or die. It is not something that any health professional is trained to do and I do not believe that that is correct.

My third concern is that if laws such as this are implemented, the perceptions of society of disability will worsen. I read some submissions by some senior citizens who do not have terminal illness, but are requesting euthanasia to be an option to them because they are concerned about the unknown; they are concerned that if in the future, "I lose my mental or physical abilities, if I become dependent on others, cannot control my bodily fluids, then I would please not like to live anymore." However, essentially they are saying that it is untenable for them to live in a way that people with disability often live every day. This sends a message to society that living in such a way, as is often the lifestyle for people with disabilities, is a poor quality of life, cannot be enjoyed and is not worth living. I think

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this sends a very negative message to people with disabilities who live like this, many who claim to have a good quality of life. Thank you for listening; they are my main concerns.

**The CHAIR:** I note that you are very passionate about advocating for people with disability and that is very valuable. We had some evidence from disability advocates. People With Disabilities WA and their national representatives came over and they submitted that if a voluntary assisted dying scheme were to be introduced, people with a disability should not be excluded from it; having and living with a disability should not be the reason for accessing it, but they should not be excluded from it if they were diagnosed with a terminal illness, which is the Victorian legislation. Could you comment on that?

**Mrs HUMBLE:** I read their submission and I think they have a very good point in general. People with disability should be treated the same as the rest of the population and disability in itself should not be a reason for dying, neither should it be a reason for holding people back from making a choice that the rest of the community can make. So, I perfectly understand what they are saying there and I agree with the principle that people with disabilities should be treated the same as others. My concern is about the risks of the system being abused for people with disability. At the moment, knowing that they already have difficulty accessing health care and community services, they are at a higher risk of choosing a choice, I would say, as compared to the rest of the population. That is not to say that one should then exclude them and say people with disability cannot have this choice and the rest of this population should. My thinking is that this is not a good choice for anybody in the community as it carries too much risk, even for people without disability who are vulnerable to coercion or who feel like my grandmother, who passed away recently, that she was perhaps being a burden to the family. There are also risks for people without disability, so my concern would be that there are not safeguards with any such legislation. I would instead support increased palliative care, and obviously the focus for people with disability needs to be better health care and access to community services.

**Hon NICK GOIRAN:** My question is really just an administrative one. I have not heard anything this morning that really would justify this session being a closed hearing. I am wondering whether you made a special request for this to be held in a closed hearing rather than as a public session? Do you have any concerns that this transcript will be released publicly?

**Mrs HUMBLE:** I did request that initially, but I am open to considering having it released publicly if I do not go into labour today or anything else!

**Hon NICK GOIRAN:** Just take me through it. What is your concern with it being made public? Do you have a concern?

**Mrs HUMBLE:** I guess it was just due to the sensitive nature of the issue. In general, I just prefer to have my opinion, but have it confidential. That is just generally how I do any submissions. But I am open to having it made public. It is something I would consider.

**Hon NICK GOIRAN:** I do not think it will be made public without your consent.

**Mrs HUMBLE:** I will just say that there is not a specific reason for it except that it is a blanket way that I operate—my personal choice.

**Hon NICK GOIRAN:** It is your normal practice.

**Mrs HUMBLE:** Yes.

**Hon ROBIN CHAPPLE:** There is comment in your submission that in places where voluntary assisted dying legislation has been introduced, palliative care has been reduced. Where do you get that information from?

**Mrs HUMBLE:** I did not bring my submission with me today. I would be happy to provide a reference for that. I apologise that reference is not in my submission.

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**The CHAIR:** Also, you provided an example in Belgium where physicians have euthanased people without consent. Can you give us actual details of that?

**Mrs HUMBLE:** That came from one of the documents that I have read and once again, can I provide the reference for the palliative care and also for the 17 per cent figure to the committee? Is that best by email?

**The CHAIR:** Yes, our staff will follow that up for you.

**Hon NICK GOIRAN:** The Belgian report is on the public record and I think it was a survey of doctors and nurses, and the survey for the nurses was even worse than it was for the doctors. I will just offer my assistance if anyone needs the document.

**The CHAIR:** Are there any other questions for the witness? Is there anything else you would like to add?

**Mrs HUMBLE:** No.

[11.20 am]

**Mr J.E. McGRATH:** If I can just make a comment, I think it would be good if your evidence was made public. I do not know what the procedure is and whether we can request it, but I think you have given some good evidence, and you do work in the field.

**Mrs HUMBLE:** I am happy to make it public.

**The CHAIR:** We can write to you with that request when we send you the transcript. We will send the transcript to you so that you can have a look first.

**Hon ROBIN CHAPPLE:** My only other comment that I think we have heard from a number of people with disabilities is that because they feel they are to a large degree of lesser status in the community generally, they need to be respected as being valid members of society, and I think we are all cognisant of that. That has come through very strongly all the time.

**Mrs HUMBLE:** Absolutely, and often in the training that we have that is specific to disability and based on what people with disability are telling us, yes, absolutely, their quality of life is often affected by society's perception of them and how easy it is to participate, more so than it is by other physical and cognitive ability, which is why I feel like there is a mismatch between what some people in society think, especially as people are concerned with approaching end of life with losing skills and their perception that it is going to be so terrible that it would be untenable suffering, that if there was actually more knowledge about disability and how successfully and how enjoyable some people find their lives who experience these issues, then it would also help to lift the perception of disability in society and also hopefully quell some people's fears about end of life.

**The CHAIR:** Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor 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 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. Staff will write with those questions on notice. If you want to have a review of that transcript and let us know in writing that you are happy for that to be made public, we can do that.

**Hearing concluded at 11.23 am**

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