

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Melbourne — 18 November 2015

#### Members

Mr Edward O’Donohue — Chair

Ms Nina Springle — Deputy Chair

Ms Margaret Fitzherbert

Mr Cesar Melhem

Mr Daniel Mulino

Ms Fiona Patten

Mrs Inga Peulich

Ms Jaclyn Symes

#### Participating Members

Mr Gordon Rich-Phillips

#### Staff

Secretary: Ms Lilian Topic

#### Witnesses

Dr Katrina Haller, chief executive officer, Right to Life Australia.

**The CHAIR** — I declare open again the Legislative Council’s Legal and Social Issues Committee public hearing in relation to the inquiry into end-of-life choices. I would like to welcome the chief executive officer of Right to Life Australia, Dr Katrina Haller. Welcome, Doctor. Thank you very much for your submission, which we have received and digested, and also for being here with us this afternoon.

Before I invite you to make some opening remarks, I will just caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1925 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today’s evidence is being recorded. You will be provided with proof versions of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee’s website. We have allowed a bit over half an hour for our time today, so once again thank you for being here with us. We invite you to make an opening submission, and thereafter we will have questions.

**Dr HALLER** — Thank you. Another part of my background is that I did a law degree in international law and human rights law and have worked in a legal centre for 12 years, mostly with respect to the rights of the child. Right to Life Australia is recommending to our supporters and members that they complete this when they complete their will. The medical part of it is only one page long — very simple. The other part of it gives you lots of options and it is very open ended. You can write what you want and do not want, we think very satisfactorily.

With end-of-life choices we can look at this at four different levels. We can look at it at the micro level, which would be the individual level. People who are in pain and suffering need proper pain relief. If they are not getting it, they need to change their doctor; they need palliative care. In extreme circumstances they may need palliative sedation.

We can look at it at the meso level, which is the level of our institutions of law and medicine. These are the cornerstone of our society, which gives us safety and security. These have a prohibition on intentional killing. What effect would any decision have on our institutions of medicine and law?

A third tier of looking at this would be the macro or societal level, which means: what does this mean for our society? What direction are we going on? What values are we embracing? How do we want our great-great-great-grandchildren to die?

We can look at it at the global level, which is the international human rights level. The Universal Declaration of Human Rights states we have an ‘inherent dignity’ with ‘equal and inalienable rights of all members of the human family’. That is, everyone has the right to life, and it is an equal right. We are equal before the law, entitled without any discrimination to the protection of the law — equal access to public services, not discriminating on the basis of sickness, disability, old age, lack of livelihood and circumstances beyond our control.

This right is inalienable, so it means that we have it because we are human beings. It is not something that the state can give to us, which implies the state cannot take it away from us. It is an inherent right to life. We cannot sell ourselves into slavery and death. Any legislation that would include euthanasia or assisted suicide would be violating this universal declaration of human rights: that everyone has an inherent right to life, which is inalienable. We cannot give that up. We do not want to violate international human rights. It has also got a strong sense of equality in the wording.

Whenever we see euthanasia discussed in the newspaper it is usually on the micro level of a particular individual. We get a lot of calls to our office from people who have disabilities, and they are afraid that they are going to be next on the list of people to be discriminated against. Since this was written, we have had the United Kingdom decision — 330 to 118 — opposed to assisted suicide. There was a group called Not Dead Yet, who campaigned against that — people with disabilities who said, ‘We get the message that our life is not worth living. We get the message that we’re better off dead. We don’t agree with that. We don’t think we’re better off dead. We don’t think our lives are not worth living’. I agree with the public advocate person previously, who said, ‘When you’re young you might think it would be the end of the world to have a particular condition, but as you get older your perspective changes, you adjust and it’s not the end of the world when you get in a particular position’.

More recently in Germany an assisted suicide bill was defeated on 6 November. That was opposed by a group of German Jews. I guess that is not surprising, that the Parliament defeated that assisted suicide bill. There have been about 125 attempts to legalise euthanasia and assisted suicide, and we have got about 196 countries in the world. Only three countries have legalised it, and one country and several states in the United States of America and Canada have legalised assisted suicide. Most of the countries in the world have rejected calls for assisted suicide and euthanasia.

Right to Life Australia would just ask that in end-of-life choices people be offered proper palliative care, pain relief — the first duty of a medical practitioner is to relieve pain, even if it shortens their life — and that they can have palliative sedation on the individual level. But we are asking also that you look at the effect this will have on medicine and law and the effect it will have on our training of doctors — how can we train students to kill people? The whole ethic of medicine and holistic of law is that we prohibit the intentional killing of people, so it will affect our institutions of medicine and law, the cornerstone of how we live, how we feel safety and security in our society. It will affect the macro level, the society level.

You people are legislators, so you are determining the path of Victoria. You are legislating for more than 5.79 million people — not this person and that person and that person. It is like a ship on the sea — you have got winds blowing in this direction and that direction. You are charting a course. So we ask that you chart a course of hope and life, not despair and death. We know politicians like to be seen kissing babies because a baby is a symbol of optimism and hope for the future, whereas despair and death, like hopelessness, is a hallmark of assisted suicide and euthanasia.

We do not really like advance care directives. We hear stories of people being admitted to hospital when they are sick and they are asked to sign this advance care directive — you know, ‘Just sign here’. Like when you are in a car accident and the tow truck driver says, ‘Just sign here’. People are not really in a position then to read what it says and understand it and think about it and decide on it. It would be better to have something that they can think about, maybe do in the presence of their lawyer, rather than when they are admitted to hospital because you might think it is a condition of getting admitted to hospital — ‘I have to sign, I don’t really know what I’m signing; I’m effectively signing my life away if it’s got lots of “Do not resuscitate”, “Do not PICC feed”, “Do not this”, “Do not that”’.

It is very inappropriate to be handed those as you are being admitted to hospital, maybe for a completely different condition. But whatever you are being treated for, something else might happen. You might have a heart attack or fall off the trolley in the corridor and hit your head or something else might happen. You do not know what is going to happen in the future. It is better to have a document that you can consider and make a decision about in calmness and time and space to make a properly considered decision. So we do not like advance care directives. I understand, though, that if there is one, then a power of attorney will prevail over an advance care directive.

**The CHAIR** — Thank you, Dr Haller, for those opening remarks. I have got a couple of questions if I may. Can you identify for the committee where Right to Life sees the difference between palliation and some form of euthanasia. We have heard a lot of evidence about this issue, and it is often a fine line, so I would be interested to know what is your organisation’s view.

**Dr HALLER** — Euthanasia — ‘eu’ means good, and ‘thanatos’ means death — it means good death, but it has been understood to mean the deliberate killing of a person in order to relieve their pain. We think people have to have their pain relieved. That is the first duty of medical practitioners. There might be a rare case where that is not possible under current palliative care regimes. That person may be given palliative sedation — but that they not be given a lethal jab, they be allowed to die from whatever fatal condition they have. They die because of the condition; they are not given an active jab.

I know there is some confusion created because there is passive euthanasia and active euthanasia. Active euthanasia is giving a person a lethal jab; passive euthanasia might be taking them off life support systems. We do not oppose passive euthanasia. We do not believe in prolonging a person’s dying — do not hasten death, but do not prolong death. Let the person die of their natural causes, but deliver all the pain relief that you can, all the comfort care that you can, and all the normal things like nutrition, like food and water. We see that as a normal thing of living; we do not see that as medical care

**The CHAIR** — The next question is: you talked about the ‘meso’, the institutional level, and the proposition that legalising euthanasia may erode or impact on our institutions. Can you point to evidence to that effect in places like Oregon or Holland or Switzerland or other jurisdictions in the US?

**Dr HALLER** — Some people in Holland are scared to go to a hospital because they think they will not come out. Medicine is about trust, is it not? You could say the law is about mistrust, but we need to trust our doctors; and doctors have as their ethic, healing, curing and relieving pain. We trust our doctors to do that. I suppose doctors might have the means to end people’s lives. That is why it is being talked about as doctors having the authority to give the lethal jab, but if we take away the medical cloak, we could say: why can lawyers not give the person a bottle of poison, especially if we are going to have so-called safeguards, because lawyers are very good at filling in forms, making sure that witnesses are not beneficiaries to the will, making sure the person understands what they have signed — checking all of those details. So you could have lawyers administering the lethal jab.

But then someone said to me, ‘Don’t be ridiculous. You can’t have lawyers going around killing people’. So if you take the medical cloak away from euthanasia — I suppose medicine makes it safe and respectable, does it not, because the medical profession is held in high regard. But it is actually opposite to what they are trained to do; they are trained to save lives and to heal lives, not to do the opposite.

**The CHAIR** — Can you provide any evidence, though, about jurisdictions where euthanasia exists? Look at Oregon, for example; the doctors do not administer the drug. It is self-administered. That has been in existence now for many years. I would be interested to know — if you want to take it on notice — if you can provide any evidence that supports your assertion in point 2 about the meso and the impact on our institutions.

**Dr HALLER** — Yes, the effect it has in institutions. Yes, I could take that on notice. A couple of things about Oregon are: two people have received letters saying the Oregon health insurance organisation will not fund their chemotherapy for their cancer, but they will fund a \$50 assisted suicide item.

**The CHAIR** — If you can provide a copy of that.

**Dr HALLER** — They were upset with that, because they said, ‘We don’t want to die. We want our chemotherapy’.

**The CHAIR** — If you could provide a copy of that letter, because we are acting on evidence and not hearsay, that would be much appreciated.

**Dr HALLER** — Yes, certainly.

**Ms SPRINGLE** — I would like to draw your attention to the issue of advance care planning and directives. You talked about and implied a level of coercion in terms of signing documents when someone is admitted into a hospital in an acute care setting. But we have heard a lot of people talk about advance care directives, the need for them and also the common practice of having them formulated when people are still well. It is very much a consensual contract of sorts that people are entering into to talk about what they want for their end of life. I would be interested to hear your response to that, because the way you framed it in your presentation was that it was a very black and white situation, where it does not appear that is necessarily always the case.

**Dr HALLER** — That is what our members tell us happens to them when they are admitted to hospital. There are two concerns about that. When you are young and not sick you cannot tell what the future is going to bring, and you cannot tell how you are going to change in relation to how your health develops. Your perspective when you are young is different from your perspective when you actually get a condition.

My 20-year-old daughter thinks it is the end of the world to be 30 years of age, but I think once she is 30 years of age, she will realise it is not the end of the world. You might think, ‘If I had this heart condition when I was 60, I would want to die’. But when you are actually 60 and you have got a heart condition your perspective changes and you do not want to die.

**Ms SPRINGLE** — Even just today we have heard from two organisations — the law institute and the Australian Nursing & Midwifery Federation — that have said it is vital that these plans are kept up to date, that they are reviewed every couple of years, for this very reason, so that people can be assured that, when they get to a point in their life that they are not as well as they had been, they are up to date.

I guess what I am describing is a document or an agreement — and hopefully that is communicated to family — that is very current and very consensual. It is not that someone is coerced into writing it. So when their wish is perhaps refusal of treatment or things that perhaps might not be considered appropriate in what you are describing, then what is your take on that?

**Dr HALLER** — Yes, that would ameliorate it, if it was kept up to date every several years or so, but we have more than 50 per cent of our population not even having a will, so that is going to be hard to get — advance care directives done by most people.

**Ms SPRINGLE** — That is what we are here for, I suppose, is it not, to try and address some of these issues.

**Dr HALLER** — And you can have a different condition. For example, Molly Meldrum could have had an advance care directive, and then suddenly he falls down from a ladder and he is not expected to live. If he had signed an advance care directive, thinking that in the future he might have some terrible thing happen, he would not be with us here now, because they would have acted on it. So you can be thinking of a general range of conditions that you might get, but then something completely out of left field happens to you and you have a different condition that you have not — who can tell the future?

**Ms PATTEN** — Thank you for your submission. I still would like to go back to the Chair's question because I think this is a really interesting area where we talk about palliative sedation. I understand Right to Life is supportive of that as a means of alleviating pain and suffering at end of life. Of course that person actually starves to death because they are sedated, so that is how they die. But it does alleviate their suffering, and I think it is something that is kind. But I go back to Rodney Syme, who says, 'I want to alleviate suffering as well at that end of life, and I do it through providing a treatment that means that they will die more quickly than if they were sedated in a palliative or terminal way'. I am trying to understand the difference between those two: in alleviating suffering through palliative sedation or through providing a treatment that would relieve that suffering but would also hasten death, because they both hasten death, one just faster than the other.

**Dr HALLER** — Yes. It is a bit like active and passive, isn't it.

**Ms PATTEN** — In a way.

**Dr HALLER** — So you can alleviate the suffering of a person by getting rid of the person, or you can alleviate the suffering of the person by pain relief or palliative sedation, and they die because of their fatal condition. They die because of their kidney failure, or they die because of their lung failure.

**Ms PATTEN** — As I am saying, they actually die because they starve, or they do not necessarily die from — —

**Dr HALLER** — We think hydration and nutrition are just normal things that people should be given. We do not think it should be classified as medical care. I eat three meals a day, but I do not consider that medical care. I do not need a doctor.

**Ms PATTEN** — No, I appreciate that. I think that sometimes in a palliative sedation perspective they are not being fed during that time because the sedation is actually about making them comfortable in those last days.

**Dr HALLER** — Yes. I think too when people are close to death their body does not have any appetite. They do not want to drink and they do not want to eat when they are a few days before death. It is like their body shuts down, and their body says 'I'm dying'.

**Ms PATTEN** — Yes, so from a Right to Life perspective, that type of terminal sedation is acceptable?

**Dr HALLER** — Yes. We are saying, 'Don't kill someone; don't do anything active to kill them', but you have to relieve pain. That is the first duty, even if it shortens a person's life. The intention is to relieve pain. It is not that the intention is to kill that person.

**The CHAIR** — Could I just ask you a question on that, Doctor? We heard from a witness a personal story about his wife who was terminally ill, and he described that his wife's death was very painful because she was unable to absorb the pain relief. Her body was physically unable to absorb it, which left her to suffer, he said, for several days in excruciating pain before she died. What would be the position of Right to Life in that sort of

scenario where, if the principal purpose of the medical practitioner is to alleviate pain, but the pain cannot be alleviated, and death is imminent? What would your view on that scenario be, that the individual puts up with the pain or that in that situation death may be hastened?

**Dr HALLER** — No, we would not agree that death might be hastened. We do not agree that anybody should kill another person. So are you saying pain relief was not possible intravenously? They were not able to — —

**The CHAIR** — This is the evidence of a witness.

**Dr HALLER** — Yes. Well, we need better pain relief research. Very hard cases do not make a good law. You are making a law for 5.8 million people, not a specific person. Your law is going to apply to every Victorian and future Victorians, so we do not want the principle of being able to kill somebody part of that.

**Mr MELHEM** — Doctor, thank you for your evidence. It is a very important issue and a very complex one. It is an issue that we are looking into as a non-political one, so we have the best view on that. On the one hand you will have people arguing for voluntary euthanasia or assisted death, full stop. On the other hand your argument is basically saying right to life at more or less all costs, even though I did hear that you were saying that passive euthanasia might be accepted. We have heard evidence from the ANMF, and their position is somewhere in the middle. I can read that to you, and I am interested in your comment on it. For example, they are happy to support a halfway position:

Competent adults with a terminal or advanced incurable illness that creates unrelievable, intolerable suffering shall have the right to choose to die with dignity in a manner acceptable to them and shall not be compelled to suffer beyond their wishes.

That is the first one. The second point:

In the case of a competent adult, with a terminal or advanced incurable illness ... unrelievable, intolerable suffering, it shall not be an offence for health practitioners to confidentially advise the sufferer and/or relatives/guardian regarding end-of-life choices; nor to assist or support the sufferer in choosing to hasten death in a manner acceptable to themselves ...

It also goes on to say that no individual practitioners or organisations should be compelled to assist in that.

Obviously talking about that there should be some sufficient safeguards in place to prevent abuse of the process, is there something you can look at or support or consider in that scenario which is proposed by the ANMF?

**Dr HALLER** — Certainly we agree with conscientious objection. Nobody should be forced to kill another person against their conscience. You talk about someone is suffering from an incurable illness. There are a lot of people with incurable illnesses that are not going to die. People with diabetes might need medication every day of their life for the next 50 years. We do not want to discriminate against people who have incurable illnesses. In Belgium people with a certain condition can be euthanased, and then 30 per cent of the euthanasia procedures that take place are on people that do have the same condition but they do not have the capacity to agree. Even though the law says they must consent, they do not have the capacity to consent. But it has resulted involuntary euthanasia of people with that 'incurable' illness.

**Mr MELHEM** — Following on from that, if we accept that passive euthanasia is already happening, do you think there will be any changes required to the current laws — for example, to protect doctors, practitioners, because we have heard there could be some concern, where I could be charged for helping someone, being passive about it, or do you think the current laws are adequate?

**Dr HALLER** — No, we think the current laws are adequate. People are not being prosecuted every day for withdrawing futile or extraordinary medical treatment. The person dies of their fatal illness — whatever that is. We do not have a duty to provide futile treatment or extraordinary treatment to anybody. They die naturally.

**Ms SPRINGLE** — So just on that, would Right to Life support the laws remaining the way they are now across the board, in terms of legislation?

**Dr HALLER** — Yes, we do.

**Ms PATTEN** — A lot of the surveys, and obviously a lot of the submissions that we have received, have been in favour of legislative change around physician-assisted suicide or voluntary euthanasia, and in fact a

number of the polls indicate that the vast majority of Australians would like to have a more proactive say at that end of life. So given the evidence that the committee has received, that a large number of people would like that, and it is the community that we are representing and that the polling is showing 80 per cent of the community would like to see change here, how do you respond to that? Should we not be responding to that majority of people who believe that they want a greater say, a greater level of autonomy, at end of life?

**Dr HALLER** — I think the very nature of human rights is that it is not subject to polls or popular opinion at any one point in time. Human rights is especially designed to protect the rights of the weak and the vulnerable, people with disabilities and the sick and the old. Everyone has an equal right to protection of their life by the law. So human rights are not subject to this particular survey or that particular survey. They are designed to do the opposite. They are designed to protect the weak and the vulnerable.

Of course surveys depend on the questions that are asked. It is often asked, ‘Do you agree with someone being in pain, or do you think they should be euthanased?’. That is not really a fair question because pain can be relieved. Also you do not make public policy on a couple of surveys. You have to consider the levels. You have to consider what effect it is going to have on society, what effect it is going to have on medicine, what effect it is going to have on law and what effect it is going to have on our agreement to abide by international human rights law. That is your job as legislators. You have to take the blue-sky view. You have to legislate for everybody, not just one particular tragic case.

**Ms PATTEN** — No, I support that. We are also looking at the evidence of Oregon, where I think they have had euthanasia for close to 15 years — between 11 and 15 years — and the evidence out of there is that people with disabilities are not feeling vulnerable. They are feeling quite protected under the regime there; that elderly people again are not feeling vulnerable. They are feeling quite protected because, possibly, of the transparency of the regime, where currently we probably have less transparency here. We are hearing the majority of the population wants to see change. We are seeing 10 years of evidence from a state like Oregon showing that that has not affected the human rights of the vulnerable. I wonder should we ignore that.

**Dr HALLER** — It is very hard to tell, is it not, if somebody is being coerced or not. It can be subtle. People with disability in the UK were saying, ‘We feel there is this message that our lives are not worth living, that we are better off dead’. Coercion can be very subtle. As a lawyer, where there is a will there are always some relatives.

**Ms PATTEN** — I suppose if you are looking at Oregon, we are talking about terminally ill patients. So we are not talking about people with a permanent disability, for example. We are talking about people who are under two doctors and have six months to live or are in insufferable pain.

**Dr HALLER** — Then you have got the case of Jeanette Hall, who was given six months to live 10 years ago. Doctors cannot make perfect predictions.

**Ms PATTEN** — So you would see that we should stay the same; we should not change a single piece of our legislation?

**Dr HALLER** — No, we should affirm our human dignity. If we abandon the respect for human life that we have, we have abandoned our humanity. I think we have to affirm our respect for human life and human dignity.

**The CHAIR** — Dr Haller, is there anything further you would like to add before we conclude — any points we have missed or things you would like to — —

**Dr HALLER** — No, just to ask that you to look at international human rights law.

**The CHAIR** — We would welcome any further information you wish to provide.

**Dr HALLER** — Yes, the Oregon experience. Thank you.

**The CHAIR** — Thank you very much, Dr Haller.

**Witness withdrew.**