TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 16 September 2015

Members

Mr Edward O'Donohue — Chair Mr Daniel Mulino
Ms Nina Springle — Deputy Chair Ms Fiona Patten
Ms Margaret Fitzherbert Mrs Inga Peulich
Mr Cesar Melhem Ms Jaclyn Symes

Participating Member

Mr Gordon Rich-Phillips

<u>Staff</u>

Secretary: Ms Lilian Topic

Witness

Mr Dan Flynn, Victorian Director, Australian Christian Lobby.

The CHAIR — I welcome Mr Dan Flynn, the Victorian director of the Australian Christian Lobby.

I will just caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 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 a proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website.

We have allowed half an hour for our session tonight. I would like to thank you very much for your preparedness to appear before us at 8.30 in the evening. Mr Flynn, I invite you to make some opening comments, and thereafter the committee will have questions.

Mr FLYNN — Thanks, Chair, and thank you very much to the committee for allowing me to appear in person on these submissions. The submissions provided by the Australian Christian Lobby cover a few aspects of the terms of reference — firstly, addressing the issue of euthanasia and indicating our opposition to euthanasia in that that would send a devastating message about the value of life and would become an option for health care that would involve taking a person's life, which is quite contrary to the ethos of medicine. I also wish to address palliative care. I call for greater resourcing of palliative care, particularly in the regions in Victoria and also to consider the advance care directives, particularly to address the concern about those advance care directives being legally binding, as is anticipated by this government.

I will perhaps just go into a few aspects of our written submission, which has been tabled. Let us address euthanasia first. We are fundamentally concerned about the message that that sends that some lives are not worth living based on some subjective standard. If someone's sense of health or worth falls below some subjective standard, then their life is not worth living, and so whether whether it be assisted suicide or euthanasia by the doctor, it is something that is contrary to the ethos of 'Do no harm'.

The position in relation to euthanasia often gets blurred. I will just quote from the Australian Medical Association's definition of euthanasia, which is:

... giving a patient a treatment or action that directly and deliberately results in their death.

What that does not involve is where assistance is provided to a patient where perhaps a life-prolonging measure is not applied or there is a withdrawal of some life-prolonging measure and/or the applying of some treatment to relieve symptoms that actually hastens death. It is clear that that is not euthanasia and the intent of those actions is not to cause death, but it may have the secondary effect of hastening death.

Sometimes we hear, even from members of Parliament, that euthanasia is happening already, but I would make the distinction that where there is an intention to relieve pain, which has a secondary effect of hastening death, that is not euthanasia. It really depends on the intent.

The concern about the deliberate and direct intervention of a doctor resulting in death is something that is simply not supported, not only by the Australian Christian Lobby but by a broad base certainly of the Christian constituency in Victoria.

The Tasmanian Parliament's inquiry in 1998, I think, was the only other time when a Parliament has inquired into euthanasia without there being a bill on the table. This Parliament is in this circumstance now. The Tasmanian Parliament concluded in 1998 that while individual cases may present a strong case for reform, the obligation of the state is to protect the right to life of all individuals equally and that could not be protected.

The concern for autonomy — and I think that is a big driver in euthanasia — wanting control over how and when we die, has to be subject to the broader public interest and the protection of the vulnerable. There has been, I think, some 10 attempts to legislate euthanasia across Australia in recent years. They have often gone to a public inquiry and they have never been successful before any Parliament in Australia, except for the Northern Territory in 1996. It was Julia Gillard who said there were no satisfactory safeguards that she could identify, or words to that effect. We have seen that concern about safeguards just in recent days with the United Kingdom's assisted dying bill, which was defeated on Friday, I think, by something like 310 votes to 118, or something of that order. Prime Minister Cameron said that he was concerned about safeguards. I suppose it is always in the detail where these things tend to fall.

There is concern about what has happened in the jurisdictions where this has been legislated, in the Netherlands and Belgium. The United Nations expressed concern in 2012 about a lax attitude towards euthanasia in Europe and noted that there were only three countries where it was in fact legal. They stated:

Euthanasia, in the sense of the intentional killing by act or omission of a dependent human being for his or her alleged benefit, must always be prohibited.

There is a case that may have been brought to your attention of some 43-year-old twins in Belgium who were born deaf. They were told they were going blind. They found a doctor who would euthanase them, and they were euthanased at 45. The proposed safeguard in that act was intolerable pain. They did not have that. But in a culture where euthanasia is a healthcare option that was available to them, tragically they took it.

There is another instance of a Belgian young lady. I think she is 24. She has been approved for euthanasia. She is suicidal, but she is not in pain as such. She is obviously in mental pain but certainly not that which was anticipated by the act. She has been approved for euthanasia. That is an indication of some of the concerns in those countries about the safeguards.

I will just turn to the concern about the reporting. Where euthanasia has been legalised in many of these countries there is about only 50 per cent of reporting of actual euthanasia deaths. Again, that represents some laxity and some concern that those euthanasia events that have not been reported may not appropriately qualify on the safeguards that have been articulated.

Australia has had one failed experiment with euthanasia in 1996, and there were concerns about the four people who died under that legislation. The report that was prepared on that by Professor Goldney indicated that there was great concern about two of the deaths, and on one of the occasions the person received the relevant counselling or assessment on the morning of the death. These are great concerns. Even where there are tight conditions they will tend to be breached, and if euthanasia becomes a right, that right will trump all concerns. It can be seen in Belgium that there are now mobile end-life units, I think they are called, that travel around and provide those services.

There is concern about elder abuse in the context of euthanasia. There is concern that people will be taken advantage of because they are a burden. They feel they are burden. In fact in Oregon where this has been studied, of those who were signing up for euthanasia, about 40 per cent of them cited being a burden as a major concern or a major indicator.

Could I just turn to palliative care. What does concern the Australian Christian Lobby is that there are very few palliative care physicians operating in Australia, or in Victoria; I will confine myself to Victoria. Some 9 out of 10 physicians operate in the city, so there is a great dearth of palliative care physicians. Could I refer you to the submissions prepared by HOPE: Preventing Euthanasia & Assisted Suicide and by Paul Russell. I am unaware whether Paul is giving evidence, but he provides a helpful table of the number of physicians involved in this and the distance from the regions. We certainly urge greater funding for that. We live in times when cures are available for complex diseases and when pain relief is definitely available.

Just finishing up on advance care directives, the Australian Christian Lobby has a concern about the Labor government's proposal to make these binding. They talk about it in terms of them being statutory. Currently the regime is that as soon as you enter into an advance care directive, it is advisory, in a sense, and the doctor will act in best medical practice. The proposal that they be binding on a doctor is very concerning. It arises from the guardianship report authored by the law reform commission in 2012, which says that there may be an offence of medical trespass if a doctor does not implement an advance care directive and that conscientious objectors would have to refer the patient to somebody else to carry out that directive. While we certainly support advance care directives — I think it is great that people are having these conversations about the sort of treatment they would like — there needs to be some caution, both on the legislative impact and on the doctor's capacity and willingness, to go against their conscience on a certain issue. Ladies and gentleman, that is my submission in a nutshell.

The CHAIR — Thanks very much, Mr Flynn, for your presentation. Perhaps I will start with the questioning. You talked about the intent being a primary consideration. I would be interested in the ACL's ethical distinction between the withdrawal of treatment — someone who is on life support or something similar

makes a decision to withdraw a treatment, which is universally agreed as being acceptable — and some active action that may hasten death.

Mr FLYNN — It is fundamentally to do with intent. That was described by Dr John Fleming when he participated in the Tasmanian committee report, and that is the differentiating moral that delineates medical end-of-life decisions from euthanasia. Administering a treatment that is intended to relieve symptoms that may have a secondary consequence of hastening death is acceptable and not continuing the life-prolonging measures is acceptable if they are being artificially done.

I will point out one thing, though, that can be a concern on this — food and hydration. There was a decision in the Gardner case that indicated that feeding through a tube of food and hydration was in fact medical treatment and that the withdrawal of that was the withdrawal of medical treatment and was acceptable. The Australian Christian Lobby would urge that food and drink be taken out of medical treatment because that is just natural sustenance for life. We would not support the withdrawing of food and liquid as something that is acceptable. But fundamentally it is about the intent, and if a treatment is delivered with the intention of ending that life, then that is not acceptable.

The CHAIR — I suppose I would make the point that if you turn off a life support system or machine, the intent or the outcome is very clear. That does not, to me, seem to make sense.

Mr FLYNN — That life support system is artificially propping up that life, and if the relatives make a decision about this artificial support, that they are happy for it to be turned off, then that is acceptable. That would have the effect that that person is going to die, but it is not intervening to kill a patient.

Ms PATTEN — I would like to follow on from that, because I think the Gardner case is interesting and I am pleased that you raised it. In that circumstance it was through PEG feeding, so one would have to say that is a fairly artificial way. I liken PEG feeding to a respirator. Once you take a respirator, which would be life support, off someone, they can no longer receive oxygen. PEG feeding is a similar thing — this person is not able to eat, so once you take them off a PEG system — —

Mr FLYNN — Yes, I think if the person is assimilating the food and hydration, it would be my submission that that is appropriate for that to continue. That food and drink is being assimilated, that person is being nourished by it, and it should not be withdrawn.

Ms PATTEN — Can I just ask, because this was raised in the Gardner case as well, about Jehovah's Witnesses refusing blood transfusions, which would be life-saving. There was the case in Newcastle where a gentleman refused blood transfusions and the doctors really tried to oppose that decision. The courts found that it was his religious belief and that they had to uphold that religious belief to not give him a blood transfusion, which ended his life. I wonder where the ACL would stand on that.

Mr FLYNN — I think that if somebody does not want a blood transfusion on that sort of religious ground, they would be entitled to take that step. That is a bit of an outlier, the Jehovah's Witness blood transfusion issue.

Ms PATTEN — Indeed, Mr Flynn, but if I had a religious belief that I did not want to be artificially fed — —

Mr FLYNN — Yes, I do hold my submission that food and drink ought to be administered if it is being assimilated into the body, but I thank you for your question, Ms Patten.

Ms SPRINGLE — My question is around advance care directives. I think it is fairly well established that modern medicine, as amazing as it is, cannot cure every single terminal illness that people have. Are you saying that you do not support advance care directives and would prefer to see them rolled back?

Mr FLYNN — No, not at all. No, we are very happy with advance care directives, but the way in which they are currently applied strikes the right balance whereby they are not binding on a doctor. So the current advance care directives — the current scheme — do not bind a doctor who is presented with a patient who arrives with an advance care directive. The advance care directive might say, 'No food, no drink, no resuscitation', and the doctor will say, 'I'm a doctor. I will resuscitate this patient'.

Ms SPRINGLE — So you support the overriding of advance care directives.

Mr FLYNN — I think Alfred Health did some work on this, and they said, 'Look, advance care directives are good, but it's also part of the conversation with the doctor. You're not going to capture on that document all the elements of this intention'. I think a doctor ought to be able to override the advance care directive, first, in circumstances to provide appropriate medical attention, or secondly, to disagree with some life-prolonging artificial set-up that may be prescribed in an advance care directive.

Ms SPRINGLE — Sorry, I am being sort of a bit nitpicky — —

Mr FLYNN — No. Good.

Ms SPRINGLE — When you talk about an appropriate medical intervention, I suppose, who is deciding what is appropriate? If an advance care directive specifically perhaps, hypothetically, indicates that the patient does not want treatment, what you are saying in that case is that they should not have that choice because the medical practitioner should appropriately override that?

Mr FLYNN — I suppose where it is appropriate. If the doctor thinks, 'Well, this amounts to suicide or doctor-assisted suicide, and I am not participating in it', then the doctor should be able to say, 'No, I will treat this patient, and I will give this patient appropriate care'. There will be clearly elements of an advance care directive that will be most appropriate and most useful, but there will be times where if it amounts to euthanasia or doctor-assisted suicide, the doctor should not have to do it.

Ms SPRINGLE — Do you accept that there is probably a fairly large grey area in there that is not either/or?

Mr FLYNN — I do, but I think ultimately in some respects — —

We are talking about autonomy here. The autonomy in some aspects is with the patient, but a lot of the autonomy in fact is with the doctor. The doctor has to make a decision: 'I am either going to take a step to intend this life to end, or I am not'. The doctor will be making that decision, so the doctor has got to not take that life, in my submission.

Ms SPRINGLE — Thank you.

Mr FLYNN — No worries.

Mr MULINO — I note there are quite a few studies referred to on pages 7 through 10 in relation to safeguards not working. I am just wondering whether you are aware of evidence in relation to a trend in the overall numbers of assisted suicides in Belgium and the Netherlands and Oregon.

Mr FLYNN — I can take that on notice and certainly get that information to you in a table or some sort of form in the next week or so. I would be very happy to do that.

Mr MULINO — Because there are some instances here of single cases that do look concerning. There have also been some instances of evidence given earlier about overall percentages or numbers being stable, so it would be interesting to know what is also happening at the more macro level — —

Mr FLYNN — What raw figures you are working on, yes.

Mr MULINO — Although there are also issues about reporting, of course.

Mr FLYNN — Yes.

Mr MULINO — Just another quick question around advance care directives. This probably overlaps a little bit with previous questions. One of the issues we are considering is ways that we can improve the advance care planning framework. I think it is generally agreed in the health sector and society more generally that it would be good if the number of people thinking about this and having discussions about this with their family and health professionals increased, and one of the issues we have on the table is binding advance care directives. Leaving aside for a moment the issue of food and water, I am just wondering —

There are issues about how explicit advance care directives should be in advance of unknowable future situations, and some people in the healthcare sector have said that they do not think they should be overly prescriptive. I am just wondering from your perspective, if somebody is very clear in an advance care directive

about something happening, what is the ethical difference in terms of what a doctor faces, in terms of complying with that versus complying with the person stating that wish in a fully competent way? Do you see those as being different from an ethical point of view for the doctor in terms of the way the doctor should respond to those two requests?

Mr FLYNN — Mr Mulino, some of the aspects of that may relate to when this advance care directive was written. If it is going to be perhaps written at a time when the patient is perfectly healthy, perhaps even 10 years before they present to a hospital, then that is a different matter perhaps to where it is written at the time that they have found themselves with some illness, and they have addressed how they want to be treated. Perhaps they do not want chemotherapy, for example; that might be written on an advance care directive. I think the doctor has got to take into account the timing and the circumstances of when that was written. The doctor has to take into account is the patient able to speak to me, or is the patient conscious? Ultimately I think there is an ethical burden on the doctor that cannot be outsourced, as it were, to that advance care directive document. I am not sure I am addressing your question.

Mr MULINO — No. I think there are complexities around when the document was signed.

Mr FLYNN — There certainly are, yes.

Mr MULINO — Yes. If you go down the path of a binding document, and it is clear. If you have a very clear document, I imagine there will be a strong argument to make that binding, but there will be complications and we can acknowledge that.

Mr FLYNN — Yes. If the doctor is being asked to do something that he or she believes is euthanasia or being asked to assist in suicide — —

Mr MULINO — Not euthanasia, just more — —

Mr FLYNN — Treatment.

Mr MULINO — Yes, or withholding treatment.

The CHAIR — Anyway, I think we have covered that. Thank you.

Mr FLYNN — It is very complex.

Ms SYMES — Thank you for your presentation. Just going back a little bit to what Ms Springle was talking about and on the doctor's interpretation of the advance care directive or advance care plan, I may have misunderstood a little bit, but I have not come across an instance where we have had a testimony where a doctor has believed that anything in an advance care plan does amount to euthanasia at this point in time. You cannot have euthanasia in an advance care plan in Victoria now, so I am just a little bit curious as to why you think a doctor should be able to override something if they think it is euthanasia. From my understanding you cannot have a directive that says 'Euthanase me' anyway.

Mr FLYNN — Sure. I wonder, Ms Symes, if something like, 'No food' or 'No hydration' — If I am admitted to hospital and I do not want any food or hydration, or if someone is admitted while unconscious, that presents the doctor with a dilemma. This patient will die if they are not fed or hydrated, so the doctor will think, 'This is not life threatening. This patient should be fed'. In a sense it is suicidal by the patient — to act on that request, even though the patient is unconscious. That dilemma does arise and could arise in an advance care directive.

Ms SYMES — Just food and water? What about somebody who says, 'I don't want to be resuscitated'?

Mr FLYNN — It would depend on the medical condition, exactly what is wrong, what that patient is being resuscitated from and in a sense what is required for resuscitation. Is it simply oxygen? I think a doctor would have a duty to address that issue and resuscitate a patient.

Ms SYMES — Irrespective of how close that person may be to death?

Mr FLYNN — There is definitely a grey area. I am not saying everything is black and white in that area.

The CHAIR — I suppose, Mr Flynn, what you are saying this evening is quite contrary to what we have heard from doctors and from a range of different hospitals and health organisations — leaving aside euthanasia — about respecting the choices of patients. We have heard evidence from healthcare professionals about the trauma that can be caused by resuscitating someone who is at the very end of their life and the damage that can be done for what might be a very short additional period of life in a very traumatic and difficult environment. It appears what you are saying is contrary to the evidence we have heard in that sort of set of parameters from a range of healthcare providers. I think your evidence this evening is quite surprising, if I can speak on behalf of the committee. It is quite surprising what you have said tonight.

Mr FLYNN — It is interesting that the law reform commission would say, 'Look, the directives need to be binding. There is medical trespass if the doctor doesn't do it, and in fact the doctor must refer to somebody who will do it if that doctor's conscience won't allow them'. There is something very mandatory flowing through the recommendations from the law reform commission, so I suppose I am flagging that that is a concern and that the doctor may feel he is having to participate in physician-assisted suicide by not doing what is obvious to him to be good medical practice to save the life that is presented to him.

Ms PATTEN — Can I just ask a follow-on from that. I appreciate that advance care directives possibly, as you said, may be written at a different time and under different circumstances. Obviously we are looking at end-of-life choices, so we are looking at a very broad range, and medical power of attorney comes into that as well. Part of that end-of-life planning is talking about introducing a medical power of attorney. If you have an end-of-life directive that says, 'Do not resuscitate. I refuse all treatments', and you have a medical power of attorney that would also say, 'These are my friend's wishes', if we were to look at advance care directive legislation, do you think the doctor should have the ability to override the medical power of attorney and the advance care directive?

Mr FLYNN — I understand the difference, of course, but I do not think anything is really added to the moral equation by having the power of attorney. You have a third party in effect saying, 'I'm authorised to make decisions on behalf of this patient', but the proposition is still the same in that a patient is effectively asking that doctor to assist — —

Ms PATTEN — Only to ignore treatment, not to be proactive. The only thing they can do is say, 'Do not provide these treatments'. They cannot say 'And actively do this'.

Mr FLYNN — Obviously if the request is 'Do not resuscitate. Do not feed', there are grave concerns about that. If it is 'Do not provide chemotherapy', I think that is quite different. I would certainly make that distinction.

Ms SYMES — You seem to have placed a large emphasis on the doctor's view, and I accept that doctors are very well trained and professional, but some of the testimony we have received from doctors is that it is their view that through their training and their work experience there is this sort of inherent culture of 'You must treat, you must save, you must provide someone with life-saving treatment'. Even doctors are saying to us that that is sometimes at odds with what is best for the patient and can prolong life rather than allowing them to die well. I guess I am just curious as to how you reconcile saying that the doctor should have a right to override some instances of a patient's choice and perhaps a family's choice when what they are trying to do is sometimes at odds with what may be best for the patient. Have I explained that right?

 \mathbf{Mr} FLYNN — Yes. It is ultimately about intent, so if the doctor is being called upon to end this patient's life — —

Ms SYMES — I am not saying they are called on to end someone's life, but they are called on not to prolong that life. Is there a difference?

Mr FLYNN — If it is, say, the withdrawal of food and drink — do not feed or drink — then you are withdrawing necessary and available food and water, and that is euthanasia in my submission and not acceptable, despite the fact that it might be in an advance care directive and it would certainly accord with the doctor's training to do that. I understand how difficult this is for doctors. I understand to a limited degree that in providing comfort to a patient who is dying and relieving their symptoms the doctor knows that that is actually going to hasten the death of that patient, but that is not the doctor's intent. That is the fault line in my submission.

The CHAIR — Mr Flynn, thank you very much for being here with us tonight.

Mr FLYNN — Thank you.

Committee adjourned.