

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Melbourne — 19 August 2015

#### Members

Mr Edward O’Donohue — Chair

Ms Nina Springle — Deputy Chair

Ms Margaret Fitzherbert

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#### Witness

Professor Julian Savulescu.

**The CHAIR** — I declare open the Legislative Council’s legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. I welcome Professor Julian Savulescu, the Uehiro chair in practical ethics; director, Oxford Uehiro Centre for Practical Ethics; director, Oxford Centre for Neuroethics; Sir Louis Matheson distinguished visiting professor, Monash University; doctoris honoris causa, University of Bucharest. Professor, we are very pleased you could join us tonight.

Before we start I 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’s 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 an hour for our session tonight, so I invite you to make some opening remarks and an opening statement, and thereafter the committee will have questions. Thanks again for being with us.

**Prof. SAVULESCU** — Thanks very much. It is a great privilege to be here. I graduated in medicine in 1989, and I did my doctorate in bioethics on end-of-life decision-making between 1990 and 1994, on good reasons to die, and worked for about 10 years on end-of-life decision-making, so I have had a keen interest in this topic. I would like to divide my remarks in terms of what I think can be achieved within the current law and, secondly, how I believe the law should be reformed.

With respect to the first issue, I am sure you are all familiar with the issue of advance care decision-making. One of the areas where I believe the law can be strengthened is to clarify people’s common-law rights to refuse any kind of treatment, including life-prolonging treatment and including treatment of any kind.

In particular, as I think part of my submission outlines, people have the right to refuse food and fluids as a part of their common-law right to refuse bodily invasion. As Ben White, Lindy Wilmott and I have argued, that right extends to the right to refuse to eat and drink by natural means — by mouth. This affords every individual control in one way over the manner in which they die. Clearly the basis of this hearing is the interest that many people have in deciding when and how they will die, one of the most important decisions that people make.

One way in which we have argued that the current law should allow people to exercise considerable control is through the refusal of food and fluids and the administration of supportive palliative care during the dying process. For example, a recent case that I heard of at Geelong involved a woman with severe motor neurone disease who was approaching the end stage of her illness and decided in consultation with her husband to refuse further food and fluid not only by PEG but by mouth. She was given palliative care and died within a short period after that. This kind of choice is open to many people not only with terminal diseases but in fact with any disease or with no disease. The ability to refuse food and fluids is a basic human right. As we have argued in our submission, palliative care ought to be provided, and the law, as we interpret it, allows the provision of palliative care for a dying patient whatever the cause.

The problem in Victoria is the Medical Treatment Act. The Medical Treatment Act was formed a number of years ago to enable people particularly to realise their common-law right to refuse medical treatment. However, it placed an exception on the refusal of food and fluids. My understanding of the background to that was to enable food and fluid by mouth to be provided as a part of palliative care for somebody who had refused medical treatment in other regards. However, this creates some uncertainty as to whether the common-law right to refuse food and fluid by any means is exempted by the Medical Treatment Act. I believe that you should as a matter of urgency clarify that people do in fact, as in the case I discussed from Geelong, have the right to refuse food and fluid by mouth and be supported in that decision.

This will give people the opportunity to die somewhere between a few days to a week to several weeks, depending on how heavily sedated and analgesed they are and their underlying conditions, but it gives people a method of exercising some control within the current law over the circumstances of their dying.

The second major thing I think this committee can do would be to legalise euthanasia, or assisted suicide. The arguments for this are very well rehearsed and philosophically quite uninteresting. There has been a large consensus that there is a strong, autonomy-based right for people to exercise control over the manner in which they die. There is a basic liberty right that if one individual wishes to end their life and another individual wishes

to help them, the state has no role in interfering in that exchange, and there are of course interest-based or beneficence-based arguments that euthanasia in some circumstances — in the case of non-competent individuals or babies — can be a justifiable procedure. I would note that neonatal euthanasia is currently practised in the Netherlands, but as a first step I believe that Victoria should be the first state to legalise assisted dying, or voluntary euthanasia.

The reason for that is that, first of all, many individuals seek this choice. It is available in other parts of the world. We have seen that it can be very safely regulated. The predictions of abuse and a slippery slope simply have not been borne out by the evidence that has just been released from the Netherlands, Belgium and Switzerland. This affords people with options that they see as fundamental to controlling their life.

The one objection that is sometimes mounted against this is that there will be coercion involved. Again, this is not borne out by the evidence. Clearly there should be safeguards against coercion, but the same sorts of concerns relate to withdrawal of treatment or withholding of treatment, the formation of advance directives, the donation of living organs such as kidneys — in all of these areas coercion can be an issue, and clearly we need safeguards against coercion. Euthanasia and assisted suicide are no different.

Let me finish by saying that I was at a conference of coroners last week. The commonest cause of death the coroners see is suicide, ahead of homicide and road traffic accidents. A large proportion of these suicides are, increasingly, elderly people who attempt to take their own life, often in horrific circumstances, such as with a broken glass through their neck when faced with going to a nursing home. I have urged the coroners to give evidence or provide a submission of the sorts of circumstances that Victorians are attempting to take their lives and indeed sometimes succeeding.

In a society that could today safely and effectively offer assistance in dying, as other countries such as the Netherlands, Belgium, Oregon and other jurisdictions have done, I think it will be inevitable that assisted dying will eventually be legalised. Every civilised society will give people this option. For those who have religious or other objections, they can clearly not avail themselves of these options. For those of us who want to exercise control over our lives and deaths, assisted suicide and euthanasia is a basic human right.

**The CHAIR** — Thanks very much, Professor, for those opening remarks. I wonder if I could ask you to expand on your comments about examples from other jurisdictions, because we have heard some evidence thus far about the slippery slope argument, and we have heard some evidence from others about the different models that exist in other jurisdictions. You mentioned Belgium, the Netherlands, Oregon and others. Could you perhaps give some further detail about which one of those models may be analogous to Victoria, or if Victoria is to go down this path, how you see this being implemented?

**Prof. SAVULESCU** — My interpretation of the evidence is that there is no evidence of an undesirable slippery slope. Sometimes you will hear the sort of data that says, ‘Increasingly this is being used for people with mental illness’, or, ‘In Belgium it’s now available for children’, or in Holland for neonates, for non-competent individuals. The argument is, ‘Look, it starts off as euthanasia, or assisted suicide, for a terminal disease, but look, in these countries it extends to involve mental illness, the incompetent and children’. In each of these jurisdictions these are very carefully thought-through extensions and, in my view, entirely appropriate.

When it comes to one ground for assisted dying — a life not worth living — probably the worst disorder you could have is intractable, prolonged, untreatable depression. It absolutely saps everything that is valuable in life. So the slippery slope to the administration of euthanasia or assisted suicide to depression is, in my view, not a slippery slope at all; it is a quite inappropriate extension. Likewise for neonates — the sorts of conditions where neonatal euthanasia has been performed have been for unbearable, untreatable suffering, such as with epidermolysis bullosa in the neonates. It is a blistering condition where the skin continually blisters off. The infant dies within a year, excruciating pain, death is inevitable. Parents have requested euthanasia, and it has been performed.

So, in my view, there is no evidence of an undesirable slippery slope from the performance of these practices in any of the jurisdictions I am aware of. In each of these countries they are enormously proud of their assisted dying laws, and they continue to support them despite perennial reviews. Probably the greatest scrutiny of any kind of medical practice has occurred around euthanasia in the Netherlands. It is simply not true that it has led to some sort of undesirable slippery slope.

What sort of model should Victoria enact? I think that is a matter of detail. You would have to look at the various legislation and decide what is most appropriate. What I would say is that I think it is a deep mistake to create any legislation that limits assisted dying to so-called terminal conditions, such as cancer. Again, in the Netherlands you have seen euthanasia performed for what is called existential suffering — people who have grown tired of life, who are simply old. Often people wish to have euthanasia before they lose any further faculties. Again, in this regard, it seems to be in some circumstances quite a reasonable choice for people over the way to end their life.

A famous case, I think, from WA is of Lisette Nigot, who took her own life after accessing drugs on the internet. She was in her 80s, perfectly well and decided that she just did not want to grow old. I think the idea that euthanasia or assisted dying should only be for conditions that would otherwise kill the patient is overly narrow. As the jurisdictions in Belgium and Holland show, it can be helpfully extended beyond that.

**Ms SPRINGLE** — Could you perhaps unpack a little bit what you think might be appropriate safeguards against abuse if there were to be legislation around voluntary euthanasia? Often there is a concern expressed around abuse of vulnerable individuals. I would be interested to hear what you think about safeguards to protect the community's most vulnerable in that situation.

**Prof. SAVULESCU** — In the Netherlands how it works is that two doctors have to sign off on any case of euthanasia, and they would be responsible if they authorised euthanasia where there was coercion involved and so found negligent. So you have a check on that. I think that is a satisfactory check, and as I have said, I have not known of any significant problem of coercion in the jurisdictions where this has been appropriate. If you were exceedingly concerned, you could authorise an independent body or an independent individual to act in the interests of the person to ensure that there was no coercion, such as a public advocate kind of role if you wanted to have additional impartial oversight, but where two doctors have to take responsibility you have the natural check that it would be a breach of their fiduciary care towards the patient if they failed, just as it would be if they acted on coerced consent for a procedure. So you have checks in place. You could implement a separate independent tier if you thought that was necessary.

**Ms PATTEN** — Professor, in your submission you speak about physician-assisted dying, and obviously something like voluntary starvation is a form of physician-assisted dying if we are palliating or providing services. I am trying to get a clear idea of the difference between physician-assisted dying, which I think can be a lot of things that we are doing right now, as opposed to physician-assisted suicide. Could you maybe tell me how you see the difference?

**Prof. SAVULESCU** — The difference is, in law and in practice, essentially the difference between active and passive euthanasia. So where a doctor either withholds or withdraws life-prolonging medical treatment and administers palliative care for symptomatic relief, even foreseeing that it may shorten life, all of that is bundled into passive euthanasia, and it is seen as being a legal practice that does not involve any intentional actions to end the patient's life. This is patently absurd when you consider that a doctor can withdraw a ventilator or withdraw a feeding tube or perform actions that will result in the patient's death, but this is called an 'omission'.

The reason it is called an omission is that if it was called an 'action', a bodily movement, it would be an act of murder. If I disconnect somebody in intensive care from a ventilator and cause their death, I will be guilty of murder. When a doctor does it, it is called an omission and allowing to die. We have managed to squeeze in certain practices around ending life that involve actions under this claim that these are somehow allowing nature to take its course or allowing to die. However, if a doctor does anything intentionally that causes death — apart from removing medical treatment! — that is then called active euthanasia, and that is illegal.

But, as I have said, I think the active withdrawal of treatment is philosophically the same as the act of giving a lethal injection that results in the person's death. They are both actions that result in the person's death. So in that sense we have already accepted, in my view, a very active assistance in dying, not merely an involvement in symptomatic relief. I think that is entirely appropriate, but it is important to recognise that every day doctors do things which result in the premature deaths of their patients.

Nobody, or virtually nobody, ever lives as long as they could live. You could always be given another antibiotic, another course of chemotherapy, more resuscitation or prolonged ventilation. In virtually all cases of dying in hospitals there is a decision made to deliver treatment, ostensibly in the patient's interests, often on the grounds of limitations of resources and sometimes at the request of patients. The three grounds of limitation of

life-prolonging treatment are: the patient has refused it, either contemporaneously or in advance; it is no longer in the patient's interests; or it is futile. In another publication I have argued that this futility justification is really a resource allocation and distributive justice decision in disguise, but that is another topic.

So I think in terms of your question there is already a lot of active assistance. I am sure people will discuss here the doctrine of double effect: the ability to give drugs that potentially shorten life but, provided the intention is to relieve pain, any shortening of life is seen as an acceptable side effect even though it is foreseeable. You will also hear people from contemporary palliative care saying, 'Narcotics don't shorten life'. It is clear in law, though, that the principle is, even if they did, that would be acceptable, provided the intention was to relieve suffering.

The adoption of double effect in my view is again attempting to squeeze in what we see as an acceptable practice within existing law. How can it make a difference whether you happen to pick out one of the foreseeable consequences of your action as being your intention and take special responsibility for that over all the other effects? How would we ever know what somebody's intention is? I think we have already in many areas allowed and created laws that allow the acceleration of dying. Why not openly give that power and responsibility over to the patient for them to make their own decision and to employ the means that are available?

**Ms PATTEN** — I guess in that case the difference between assisted dying and assisted suicide is when the patient makes that decision. Then it becomes suicide, obviously.

**Prof. SAVULESCU** — Assisted dying is broadly anything that is giving any assistance, including palliative care, to a patient who is dying. Assisted suicide is where the person themselves decides, 'I want to die now', and assistance is provided to bring that end about. That is assisted suicide.

**Ms FITZHERBERT** — You were speaking earlier about a list of circumstances and sort of types of people who in your view should be able to end their lives or have their lives ended for them. To look at it the other way, who should not be allowed to?

**Prof. SAVULESCU** — I think people who are incompetent — in cases of children or adults who are incompetent by virtue of mental illness — are a special category where the decision-making process would need to be different, and I think it is much more controversial. In my view I think that is the most controversial area. I think it is very difficult, having studied in this area for 10 or 15 years, to outline what is a life that is not worth living, even though this is meant to be a ground for euthanasia. I think there are some cases, such as epidermolysis bullosa or maybe Lesch-Nyhan disease, but there are very few, so I think that is a very difficult area.

In those people who are competent, who can express their own desires about their own life, I think it is a mistake to try to show that their life is somehow not worth living. They have the liberty right to control and end their life when they wish, so I would draw the line between those who are competent and incompetent.

I think the case of legislating — although in principle I support it — non-voluntary euthanasia for incompetent individuals is in principle justifiable, but is a very difficult area to legislate. The much easier area is for competent individuals. The difficult cases, I think, are where an individual is competent now and says, 'When I become incompetent, not only do I refuse life-prolonging medical treatment, but I request euthanasia if, for example, I can no longer recognise my family and no longer recognise myself. If I have Alzheimer's disease to such an extent that I can no longer engage in meaningful social aspects, at that point not only do I want to refuse medical treatment, I want to die'. That, I think, is a very difficult case — the most, if you like, difficult case within the voluntary euthanasia spectrum.

I think you fall on one of two sides. You either believe the individual has already died by that stage in a biographical sense and that their life is really over. There is a body that is continuing to live and, if you like, some other kind of being occupying their body. They are essentially two individuals and one individual has already died. Or you take the view that we have a right to control what happens to our body after our death, such as through wills, and the right to have euthanasia performed is still a right that that individual has.

I would err on the side of giving individuals the right to control how they die, and if they believe that is not an existence they want to continue to live in, they should be given that opportunity.

**Ms FITZHERBERT** — Can I follow up? You mentioned earlier the situation where someone was competent but has ceased to be competent or wants to make arrangements anticipating that they may become incompetent at a later time. That is obviously an issue that many people have raised with us. Do you have any specific legislative changes that you would suggest which might address that area?

**Prof. SAVULESCU** — Again, I have just come back from running a hypothetical on exactly this topic in Ballarat, and there is considerable division, particularly from the AMA, over whether you ought to respect even advance directives that apply to the withholding of life-prolonging treatment at some future point of incompetence with Alzheimer's disease.

My first point would be that there is no real or ethically significant distinction between an advance directive that refuses life-prolonging treatment and an advance directive that requests active euthanasia, so I think you have to deal with them in the same way. Many doctors believe that that advance directive no longer applies if that individual is happy and in other regards is appearing to lead a worthwhile life.

I believe you ought to legislate to make it clearer — and this is contentious — that the advance directive does apply. Even if they have what is a worthwhile life and even if they are happy, their ability to make decisions — either for active euthanasia or the withholding of or withdrawing of life-prolonging medical treatment — ought to be respected. People ought to know that their wishes either will or will not be respected in that situation.

Many people are filling in these advance directives thinking that they will be respected when in practice they are not because there is no clarity about whether they apply, particularly across long periods of time, to periods of incompetence. The hypothetical we had was one that was formed 10 years before. The point I made there was that the mere fact that a wish was expressed 10 years prior is not a reason to disregard it. If I write my will now and I die 10 years later, it is still respected.

What is very important with advance decision-making is that it is clearly established and applicable in the circumstances — that is, that the directive really applies to that situation and that the person has not changed their mind. Provided that those two criteria are satisfied, it ought to be respected in the same way that a will ought to be respected. But the challenge is to ensure that there are processes in place that demonstrate that it is continuing to be the person's desire and the range of circumstances it is meant to apply to. Here is an advance directive that is very easy to interpret: 'If I ever become so demented I cannot recognise myself or other people, don't keep me alive'. Provided I do not change my mind, there will be certain decisions that might be made at such a point that I get dementia.

So I think that some level of clarity about the application of directives across time, particularly in cases where the individual appears to have a life that is worth living but not one that the competent individual previously wished to be in, is an area that requires clarification.

**Ms FITZHERBERT** — You said in your answer then that there are situations where people's advance directives are not respected. I do not doubt what you are saying, but where is the evidence of that? Is that an anecdotal view or is there some way of — —

**Prof. SAVULESCU** — During the hypothetical, half of the medical staff present would not respect it. Again, I do not have the data. Talking with many of my colleagues in advance care planning, the view is often that this advance directive is not interpretable in the circumstances. It is not applicable. It has been such a long period of time and we cannot use it in practice. So it comes down to their ability to interpret them. But you had best talk to my clinical colleagues. My prediction is that they will say that in many cases they are not respected. Compare that to a Jehovah's Witness directive that says, 'Don't give me blood under any circumstances', which is respected, even if it was formed 10 years before.

**Mr MULINO** — Thanks for your evidence, Professor. You have argued that based on notions of autonomy and liberty, if one were to take that to the point of justifying an active euthanasia regime, that would lead one to argue for quite a broad set of arrangements for competent people and that should not be viewed as a slippery slope. It is just applying that ethical framework to each situation. I am just wondering whether you would worry about situations such as somebody, for example, having a horrific accident and being blinded or becoming a quadriplegic, where there are well-documented cases of people going through potentially quite prolonged periods of depression and there being a degree of uncertainty around how long that might last. Would you have

concerns about safeguards around, for example, two doctors signing off on something not being sufficient to protect against the reversibility of what somebody might be feeling?

**Prof. SAVULESCU** — I think that is a very good point. Adaptation is a human regular. If you look at how badly people think paraplegia is, they think it is very bad. Once they become a paraplegic they rate their life very low, but then some years later their ratings come back almost to normal. I think that is a good argument for having a cooling-off period — perhaps a year, perhaps two years — after a major accident, where the person does not have a terminal illness but has a severe deficit in their quality of life.

There was a case in the UK a year or two ago of a young man — I think he was 18, 19 or 20 — who was rendered a quadriplegic in a rugby accident, and after nine months as a quadriplegic his family took him to Dignitas in Switzerland, where he had an assisted suicide. There was a lot of concern that he had not yet adapted to his quality of life. My view on that case is that he had had some period. Now how long that period should be is a psychological question, not one that I am fit to answer. Is it nine months or is it two years? What is clear is it is not for the rest of your life. You have to draw a line at some point and say, 'We've given this enough'. It is the same with depression. You would not want to be performing euthanasia for somebody who had had their first episode of depression after six months. But after 10 years of depression, at some point I think people are entitled to say, 'It's enough. This life is enough for me'. So I think that is an important question, but one that should not preclude the formation of legislation to allow euthanasia. It is a requirement for a certain period to enable whatever adaptation can occur.

I should say, though, that it is interesting in this regard, although I am supportive of having such a period, that it is inconsistent with our approaches to passive euthanasia. I can be rendered a ventilator-dependent quadriplegic tomorrow, and a week later I can refuse to have continued ventilation, which will result in my death. Whether I die or not, in common law you can refuse to have any kind of medical treatment, including ventilation. In common law I can refuse to be kept alive and die immediately, but I cannot ask for active euthanasia.

Whether you live or die happens to depend just on whether you need some kind of medical assistance to keep you alive, but that is not really the morally relevant question. The real question is, 'Is this a life that is worth living?' and/or, 'Do you have the right to choose to die in this circumstance?'. Clearly people do have the right to die by refusing life-prolonging medical treatment whatever the circumstance.

I would personally prefer that people be supported and given advice, given education and given counselling in order to encourage them to sit out their quadriplegia and try to adapt in the best way that they can, but I again do not believe that if they are competent, it is a good ground to override their freedom. In the same way as we might allow them to die by refusing life-prolonging treatment, we could assist their dying with euthanasia.

In the case of the rugby player from Wales I think he was, I think it was entirely the appropriate decision. In fact on the back of that, Keir Starmer, the director of public prosecutions — this is something again Victoria could do — issued a whole set of criteria about when the DPP would investigate assistance in dying and when they would not. Technically these people are clearly assisting his suicide — they are taking him to Zurich for a lethal injection — but again the law has bent itself to allow that range of practices. I think that some clarification in Victoria about what constitutes assistance in dying would be useful as well, if the law was not liberalised.

**Mr MULINO** — An unrelated issue but similar vein in terms of some of the difficulties of implementing a scheme in practice, one of the issues that is raised is coercion, but often people might feel it in a very subtle way, where people might feel like they are a burden and in a way where they cannot even necessarily vocalise it to their families because that would add to their guilt. That makes it difficult in a lot of ways — those kinds of subjective feelings — to rigorously evaluate the impacts of schemes. I have seen a few varying outcomes from evaluations, which I suspect might be different approaches methodologically to try to tap into that. Is that an area that you think is potentially problematic to protect through safeguards?

**Prof. SAVULESCU** — When I have talked to people in the Netherlands, I have said, I thought you were an extremely advanced country. You must have had all this philosophical discussion about euthanasia to create these laws', and they said, 'No, it was created out of fear'. People fear dying. In fact — and this is another very common phenomenon — many people do not avail themselves of it. They just want to know the choice is there if they need it, and they found it extremely liberating. My experience discussing it — and this is not a systematic study — is that people value the option.

It is also important, I think, to recognise that people may choose to die for other regarding reasons, because they really do not want to be a burden to their family or to society, and that is not wrong. That is not necessarily coercion. It could be an altruistic kind of act. So I think that you have to be very careful just to pull out the spectre of acting with regard to other people as an overwhelming reason. Potentially it is a problem, but it is also a problem with refusing medical treatment or completing advance directives, as I said before.

The concern is the family is going to coerce this individual to get their money. That can happen when you appoint them as an enduring power of medical attorney. We put individuals in charge of decision-making about whether that individual lives or dies. That individual is vastly more empowered than in the case of voluntary euthanasia — they can actually just decide to stop treatment now. So if we accept that individuals can place somebody in a trusted circumstance to make decisions about whether they live or die, then presumably they can appoint somebody to tell us whether these are really that individual's wishes or whether there is coercion going on. You could extend the enduring power of attorney to give some kind of check and allow a person that that person nominates to evaluate the situation as to whether it is really that individual's wishes or whether they are acting under somebody else's pressure.

But no system will be foolproof. I am sure there will be some cases of coercion; I am sure that will happen. Maybe we will hear someone cite a case where an individual has been coerced. Of course that will happen. People die today who did not want to die. The point is, overall will this benefit a very large number of people with an acceptable level of risk? You will not ever be able to eliminate every single risk of an adverse event in any human system — it is just impossible. I think you can put in safeguards to minimise the risk of coercion. As I said, there is just no data that has come out after 15 or 20 years of these practices that has shown that this is a significant problem, despite a large group of the community being desperate to find any kind of cases they can to shut down the practice. As I said, it has been an extremely scrutinised practice. I see it is a potential problem, but I think it is a problem that society can accommodate and deal with.

**Ms SYMES** — Thank you, Professor. I note your view that the statute laws should be clarified in relation to the refusal of food and fluid and then the discussion about your views about voluntary euthanasia with some safeguards not limited to terminal illness. Considering the two ends of those proposals and given that it is very often the case that changes to the law, particularly in areas that are sensitive, need to be staged, are there any smaller steps in between those two positions that you think would lead to the right direction in the law that supports where you would like to go? I am thinking, just looking at some of your organ donation euthanasia, whether there are some first steps that you would be encouraged by.

**Prof. SAVULESCU** — The least controversial step, because I think it is legal now, is just to clarify that people can choose to die by refusing to eat or drink and can receive palliative care. I think we are there in some states. Victoria, because of the Medical Treatment Act, introduces some uncertainty, and you could clarify that uncertainty. That is a form of slow, assisted dying that will take place over weeks. Faced with the option of continuing life with a very severe illness, that may be attractive to more people if they knew that it was available. I think that is the first. The next step is assisted suicide for medical conditions — physical medical conditions. The Northern Territory's euthanasia law focused on terminal physical conditions, and that I think is one that is totally uncontroversial. If you are going to die within a period of a year, and if you wish to die now and if that diagnosis is clear, then that is something that people ought to be able to have the choice over. You are not creating any real excess deaths.

An assisted suicide is one where the person has to make the final decision — they have to administer the injection or take the medication — so there is a clear indication of intent on their part. Then I think euthanasia for those people who are incapable of taking their life because of paralysis or a neurological condition is the next reasonable extension. Then the final extension, the one people find most difficulty with, is either where there is no clearly defined illness, such as ageing, or where there is some kind of mental illness that is afflicting the person. I think that if you can get in place the safeguards against coercion in the simpler cases where the person is going to die, then those can be used to reassure people.

That is as I would see the progression: first of all giving greater control using the ability to refuse, and that might extend to cases of Alzheimer's disease, refusing life prolonging treatment in Alzheimer's disease or dementia when you are incompetent, to then semi-active means, which is assisted suicide where you still take an action. I should say here that one of the things I have heard time and again is that one of the bodies that is most vigorously opposed to euthanasia is the AMA and doctors. I guess there are a number of reasons for this,

and I think it is important to separate assisted suicide and euthanasia from physician-assisted suicide and physician-administered euthanasia. It does not have to be done by a doctor. There are arguments for and against, and I think that is a separate debate. When you hear the AMA say, ‘We do not want it, we are opposed to it’, that is fine. Nobody should have to administer euthanasia or assisted suicide if they do not want to — unless we are in the extraordinary situation that it is legalised and no-one will do it, but that is unlikely to be the case. I do not think that it has to be medically assisted suicide or euthanasia necessarily.

**The CHAIR** — If I could follow up your answer in response to Mr Mulino’s first question, when you talked about the cooling-off period and a certain period of time and then talked about the complexity of identifying what that might be depending on the condition, the age, the mental state et cetera of the individual that may be the subject of the particular subject. How have other jurisdictions dealt with that question?

**Prof. SAVULESCU** — Sorry, which question?

**The CHAIR** — The cooling-off period question. What is an appropriate period of time for a cooling-off period for an individual, depending on their age — —

**Prof. SAVULESCU** — I cannot remember the cooling-off periods for different jurisdictions. I am trying to remember what it was in the Northern Territory, I think it was six months, but I do not know what the cooling-off periods are. I think it is not necessarily one you want to copy. I think that if you are concerned about adaptation, that is a psychological question that you would want to be scientifically informed for, if that was the reason for doing it. But remember that the longer the cooling-off period, the greater the infringement of liberty, so there is a cost, but I do not know the answer to the cooling-off periods.

**Ms PATTEN** — I was reading with interest your palliative starving arguments and I recalled that at another hearing we had a doctor talking about advance care planning and about having that conversation. You might be looking at the television and see a woman with dementia sitting in the corner of a nursing home on a documentary and say, ‘If I’m ever like that, kill me’. I think that is something that is not uncommon. Are there any jurisdictions where in an advance care plan there is room for a more proactive assisted dying? In that circumstance in Australia we might be able to say that she would no longer take food or antibiotics and eventually she would die.

**Prof. SAVULESCU** — I believe — but you would need to check this — that has been done in the Netherlands. Again you will hear that there has been a slippery slope to non-voluntary euthanasia involving people who are incompetent. It is usually in the case of previously expressed wishes about that. I think you would need to check that.

**Mr MULINO** — I have a question. I just want to go back to what might be called a slightly more generic and abstract point about the ethical distinction or non-distinction between active and passive. My sense would be that if one were to look at a right of refusal of treatment, that would largely stem from notions of autonomy over one’s body. If one were to try to ethically justify something more active where another person became involved, that would be more about — I think you referred to it as liberty — the rights of two people to engage in an arrangement that did not harm others and was mutually agreed upon.

**Prof. SAVULESCU** — Yes.

**Mr MULINO** — You have largely said they are ethically quite similar. I suppose my sense is that there can often be distinctions. One example that I am thinking of is an analogy in a totally different sphere, but it is just my way of thinking about it in terms of commonly understood regulatory arrangements. We often regulate, for example, financial transactions that people are engaged in or other transactions through consumer law. We do not consider it unethical for an individual person to try to enter into a transaction that is seriously to their detriment. They might be competent but just not particularly well informed. But we do consider it to be unethical for that transaction to occur, and we will often prohibit the other party from entering into that transaction with them and say that the contract is void. Is it not fair to say that there can often be quite a distinction once it involves two people?

**Prof. SAVULESCU** — I can understand if you are concerned with vulnerable individuals who are not competent to make their own decisions. I can understand that you will say, ‘Okay, we’re not going to allow this kind of transaction when it involves a life that is clearly worth living’ — for example, for anorexia you might

say, 'We're not going to allow euthanasia for anorexia'. But in those cases that we are really discussing, where an individual has a severe physical and mental illness or is suffering from ageing, it is their life, and it is their body. Provided that they are competent, I cannot see what role there is for the state to be involved in that transaction. It is their life. It may be entirely appropriate to prevent certain types of financial transactions based on differences in knowledge and power. But in end of life cases, we are considering an individual's wishes for his or her own life, a matter which he or she has privileged access into knowledge of and power over. If they know anything or can do anything, it is in relation to their own life. Precedents over prohibiting other kinds of competent transactions don't apply here.

If there was diminished competence as a result of mental illness, then I can see that we would need to protect people with mental illness, but the downside of that is that you may be consigning people with mental illness to a life that really is amongst the worst. But I can see again as a protection that that might be an area of transaction that you do not allow. But if somebody is fully competent, and they have motor neurone disease, you would have to show me how it is that they are not fit to make that kind of transaction. Very often what is in the background is a belief in the sanctity of life that other people hold.

The reason we have had laws against suicide, euthanasia and assisted suicide for many years is twofold. One is that your body belonged to the king, and you had to be fit for fighting. The second one is that your body belonged to God. I do not hold either of those myself. My body and my life are my own, and if I want to end it, that is not something that other people's views on the sanctity of life should dominate. It is fine for their lives. They should live their lives according to that. I do not see, at least in a subset of these desires, why it is not a transaction that is fit to occur.

**Mr MULINO** — I certainly was not trying to put anything along those lines. I guess I am just thinking that the ethics, I imagine, do get a bit more complex when other people become involved. To me, the ethics seem simpler when it is autonomy. That is all I am saying.

**Prof. SAVULESCU** — I think in some ways it is simpler, but in a lot of ways it is not. The two essential questions are, 'What makes life worth living?', and, 'What sorts of rights or freedoms do we have over our own lives?'. It seems to me that if you allow Jehovah's Witness kids who are perfectly fit and healthy and could make a complete recovery to die, you have made a decision about the importance of people's liberty, in my view, for totally irrational reasons — reasons that are not even shared by the other denominations of Christianity — over a literal interpretation of the Bible.

Why do the rest of us not have a similar kind of power over our own lives? It is not about refusing or getting help; it is really about what we should be able to control about our lives and what is worthwhile in our lives. Those questions are the same, whether it is refusing treatment or accepting euthanasia. It is true that some people will give up lives that are worth living — absolutely; that is the price of freedom. So it is a question of whether we have freedom over our lives or we do not. If we have freedom over anything, it should be over our own lives, as the Jehovah's Witness example shows nicely.

**Ms PATTEN** — I am sad because that seemed like such a great place to stop. Is there a jurisdiction that you think has a model that would work in Australia?

**Prof. SAVULESCU** — As I said, I started my doctorate in this and spent 10 years on it. I thought change would occur in the 1990s. I became so bored with it I stopped keeping up with the detail, so I do not know the details of the legislation. I think the challenge for you is to make the best legislation possible. You can do that. You have got lots of trial runs. You have got ecological experiments. You have got countries all over the world. You can do better than that. I think it is time that Australia corrects the massive mistake of overturning the Northern Territory's entirely legal and appropriately formed legislation and comes into the 21st century — after it almost did.

**The CHAIR** — Professor, thank you very much for your time.

**Prof. SAVULESCU** — Are you clear enough about which side I fall on?

**The CHAIR** — You have given the committee very clear evidence. Thank you very much. It is greatly appreciated.

**Witness withdrew.**