

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Melbourne — 15 October 2015

Members

Mr Edward O’Donohue — Chair

Mrs Inga Peulich

Mr Daniel Mulino

Ms Nina Springle

Ms Fiona Patten

Staff

Secretary: Ms Lilian Topic

Witness

Dr Ken Harvey, Member, Doctors for Voluntary Euthanasia Choice.

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. Welcome to Dr Ken Harvey, adjunct associate professor, department of epidemiology and preventive medicine, school of public health and preventive medicine, Monash University. Before I invite you to make some opening remarks, I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and is 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 the proof version in the next week or so, and transcripts will ultimately be made public. We have allowed 45 minutes for you this afternoon. I invite you to make some opening remarks and thereafter the committee will have questions.

Dr HARVEY — First of all, again thanks to the committee for allowing me to make a presentation on behalf of Doctors for Voluntary Euthanasia Choice. We are a national organisation of Australian medical practitioners, both current and retired, who are working towards having voluntary euthanasia legalised for patients with intolerable, incurable and unrelievable symptoms. Assistance may be by doctor provision of medication for patients to consume or, if a patient particularly requests help, by doctor administration. As well as aiming to legalise voluntary euthanasia, we advocate that professional medical bodies should adopt or maintain a neutral stand towards legislation in order to reflect the views of their membership, which are invariably varied.

We provide evidence that the practice of voluntary euthanasia can be ethical. It is actively sought for by patients in Australia and is acceptable to the majority of Australians. We convey this evidence through courteous communication to professional medical bodies, to politicians and to the general public through the media, usually through writing letters but also by encouraging and participating in public education and debate. For example, one of my own activities in this regard is to run an eight-week course for the University of the Third Age, Melbourne City, entitled Health Care Interventions: Choosing Wisely. In fact I have just come from this course this morning to you.

In this course we discuss end-of-life issues such as dying with dignity, advance health care directives, refusal of treatment and enduring medical power of attorney certificates. We also review short videos aimed at improving communication between doctors and patients on end-of-life planning, and I have one very short one that you might like to view at the end of my presentation. Participants in this course often share their end-of-life experiences that they have had with dying partners and or relatives, and, regrettably, a number of these stories are not happy ones. The problems experienced include uncontrolled pain; suffering and loss of dignity because of faecal and urinary incontinence; lack of autonomy, with advance health care directives being ignored, particularly by nursing home staff and often also on acute admission to hospital in a crisis; and lingering and slow death from voluntary refusal of treatment, including food and fluid.

Medical ethics currently commits practices that amount to assisting hastening death with a patient’s consent. These include refraining from administering or discontinuing life-sustaining treatment, administering medication in doses which may hasten death, and palliative sedation. All of these are legal, as long as causing death is not the doctor’s prime intent — the double effect doctrine. But as many people have pointed out, the differences between these practices and physician-assisted voluntary euthanasia is illogical and ethically inconsistent. The consensual withdrawal or removal of life-sustaining treatment from a patient is legal even if this action results in a patient’s death. The consensual administration of drugs to shorten a patient’s life in order to relieve intolerable and unrelievable symptoms is illegal, and the inconsistency of this and the legal illogicality of this is obvious and we believe discriminatory.

Currently many medical practitioners may not provide such measures because of legal uncertainty for fear of complaint and concern about prosecution for murder, manslaughter and aiding and abetting suicide. We believe this legal uncertainty must be clarified in new Victorian legislation. There should be no civil or criminal liability if measures, including physician-assisted death, are taken in accord with ethical practice and the patient’s express desire to relieve intolerable, incurable and unrelievable symptoms.

Palliative care and physician-assisted death are not mutually exclusive. We support the former and it should be universally provided at a high level, and regrettably it is not provided to all at the moment, which it should be. But equally, physician-assisted death should be available as a last resort option. Other submissions such as that

from Dying with Dignity Victoria have reviewed overseas practice with respect to voluntary euthanasia and have listed key safeguards put in place to prevent abuse.

In conclusion, Doctors for Voluntary Euthanasia Choice believe it is time that Victoria joined Canada and an increasing number of other jurisdictions in the legalising of voluntary euthanasia. I table this statement and also a relevant editorial from the *New England Journal of Medicine* about the recent Canadian decision. I have a short video on doctor-patient communication that you may find relevant.

Video shown.

Dr HARVEY — I think it is of crucial importance that we have these discussions, both with consumers, patients and doctors. I think it is a nice example of a training video that actually shows how not to do it. But that is one of the reasons again why I run the University of the Third Age course, so that we can have some frank discussions about these issues.

The CHAIR — Thanks very much for your presentation, Doctor, and I appreciate your evidence. First of all I would be interested to know what sort of membership there is of Doctors for Voluntary Euthanasia Choice and I suppose more broadly, as much as you can, what percentage or what sort of proportion of the medical profession would hold a similar view to you, because from our deliberations we have heard conflicting opinions?

Dr HARVEY — Yes, clearly there is a diversity of opinion on this topic. In terms of our organisation, currently there are around 130 members, but we are one of a number of organisations. A number of surveys have been conducted. They are listed on our website, and they are also in the Dying with Dignity submission. I think overall probably around 50 per cent of doctors would agree under some circumstances that it is appropriate to assist a patient in relieving unbearable suffering, and obviously with patients that is higher. A number of surveys have shown — again it has increased — it is probably up to 70 per cent or so now, but, again, I respect the views of my colleagues that would dissent from such action and I think that is perfectly reasonable. Obviously some people with particularly religious views would not believe in going down that path, but I do think, like other people in which religious views conflict with the need to help a patient, then there is some obligation nevertheless to refer those people to other practitioners who would have different views. It is certainly not universal amongst my colleagues, but I think it is now probably over 50 per cent.

The CHAIR — Okay, thank you. I am not sure if you were here for Professor Kissane, who gave evidence before we had a break.

Dr HARVEY — Yes, I have read his submission.

The CHAIR — I would be interested in your response, if I can try to summarise it, to his position: that a significant proportion of the people who seek out physician-assisted dying do so out of a fear about the unknown and that many of their concerns can be ameliorated or resolved through appropriate treatment — whether that is a psychological issue or health-related and palliation — and that for the, as he would suggest, small minority that do not fit within those categories it is not worth the impact on the broader system of legislative change to allow euthanasia to accommodate that very small number.

Dr HARVEY — I understand those views. I do not accept them. I certainly am very supportive of increasing the capability of palliative care, and I think you have heard from Barwon Health that really we are not getting enough palliative care available. Certainly in our own written submission we made the point that depending on where you live in the country there are very poor resources. Again, as we have said, I am very supportive of increasing resources for palliative care.

Having said all that, I would dispute that it is a minutely small proportion of people that end up not being helped. I think the figures are something like 5 to 10 per cent of people for whom, even with very effective palliative care, their symptoms are not controlled. I think again there is a question of whether their autonomy should be respected in this regard. The argument against is the slippery slope argument. I do not accept that. I think that with appropriate safeguards — and a number of submissions put down appropriate safeguards and have listed also the safeguards in other jurisdictions — the slippery slope can be prevented.

Again, it ends up really as: what is more important? To me, a physician's duty is to relieve suffering. It seems to me that if suffering cannot be relieved by all the advances we have in modern medical care and palliative care, if a patient with their full knowledge requests over a period of time to have their suffering eased by voluntary euthanasia, if there is discussion with several independent physicians and a psychiatrist, if indeed there is concern about mental problems and depression and if after all that it is agreed that no more can be done, then I think accepting a patient's wishes is reasonable.

The CHAIR — To continue the point, you do not accept the proposition that if you agree to that course of action, as you are suggesting, that has a broader impact on the provision of health care and for some medical practitioners it would perhaps be seen as an easy option rather than complex, difficult, challenging, expensive, lengthy palliative care?

Dr HARVEY — End of life is a messy and difficult situation. Again, I think you have heard from a number of submissions that not all medical practitioners are well trained — and not all patients accept or take advantage of the opportunities to actually discuss these issues and understand these issues and make advance healthcare directives which can assist people in choice. I think we need much more in terms of public education, and that is certainly one of the reasons that I work with the University of the Third Age on this now. But having said all that, people do make bad choices. People commit suicide by gunshots, by jumping off bridges et cetera. There are untoward consequences of allowing people autonomy and allowing them to make their own decisions. I personally do not believe that allowing physician-assisted suicide with all the appropriate safeguards, I have suggested, would lead to floodgates and slippery slopes or other people taking advantage of it.

At the moment we have elder abuse. We have people bringing pressure on elderly relatives to pass across their estate and financial institutions. Again, good dialogue with lawyers and health practitioners can, I think, avert those problems. I think the sorts of measures I have outlined, where the patient has got to be seen to be competent with several physicians and if necessary a psychiatrist involved, if some time is taken, I think these can prevent the sorts of problems that are alluded to.

Ms PATTEN — I am not sure about Mr O'Donohue's question. The question that was raised with us with the previous testimony was that a person who wanted to hasten their death at the end of life was probably suffering from depression or a mental health issue and that with good psychiatric treatment that person would no longer see the need for that. Do you think there would be some people who would benefit from psychiatric treatment, or can a patient really at the end of their life say, 'I've had a good life and now it's fine'?

Dr HARVEY — I accept that proposition. Having said that, clearly depression is part of incurable illnesses on a number of occasions and can be alleviated with treatment — at least that aspect. The fact that if one is dying, one is leaving this world, leaving your loved ones and your children causes some existential angst, and that is —

Ms PATTEN — Natural.

Dr HARVEY — natural and cannot be relieved with antidepressants. Again, I support good palliative care, relief of pain when you can and the use of antidepressants when appropriate. But having said all that, I agree with you. There are patients who get to the end of the journey and want it sped up because they believe the time is right and their suffering is intolerable, is not meaningful and is distressing to them, and it is time to bring it to an end. I personally support a choice under those circumstances.

Ms PATTEN — I do not know if you can answer this, but I wonder why so many doctors that we have spoken to are so vehemently opposed to this proposition. I am trying to understand from a professional aspect why that might be.

Dr HARVEY — I wonder whether the doctors who come along are a representative sample of the population. I have mentioned that there have been surveys of my colleagues that would show that probably a little over 50 per cent, sometimes more, support under stringent circumstances physician-assisted death. Clearly there are some of my colleagues with very strong religious views who under no circumstance would want to go down this path and are worried about the consequences. There are others who fear that sort of decision-making. But again this is not too different from the situation, for example, of providing abortions. I am aware that some of my colleagues would oppose it on a variety of religious or other grounds. Again, they do not have to do it, but we would ask that they would refer a patient to someone who would under those circumstances.

I have no problem with the diversity of opinion amongst my colleagues. Again, I have no problem with them making decisions on their own conscience. All I would ask is that they do not impose their views on everyone and that if the majority of the community are in favour — and I certainly believe the majority of the general public is in favour — something like 70 per cent are in favour of doctor-assisted death under exceptional circumstances, then I think we should provide it. I was actually interested to read the Canadian decisions, and I think the editorial I have provided you summarises the legal situation quite nicely about how the decision was that the autonomy of the person, really, is the most important thing and that they should be allowed free choice in these matters.

Mr MULINO — Thanks for your submission and your evidence. I just wanted to clarify I suppose the conditions under which you would recommend that it be available. You used the phrase ‘intolerable, incurable and unrelievable symptoms’ — —

Dr HARVEY — And suffering.

Mr MULINO — Yes. That is similar to the Belgian framing, is it fair to say? It is a bit broader than terminal.

Dr HARVEY — It does not restrict to terminal illness, because there are some illnesses, as I think have been pointed out in many of the submissions — motor neurone disease, multiple sclerosis end stages et cetera — where the condition is not terminal but the suffering can be intolerable and unrelieved. So my own view, and certainly the view of Doctors for Voluntary Euthanasia, is that the broader definition is appropriate.

I accept that some of my colleagues would think it is a smaller step to go to put ‘terminal illness’, but I think if one looks at the patients who have requested it — certainly, from the stories I have heard from people in my courses — it is appropriate to say unrelieved symptoms that are incapable of being properly controlled, and that can be in a number of situations, again, after all due process of looking at depression and consultations with experts in palliative care and psychiatry have been undertaken. Having said all that, there are a small number of people who have not got terminal conditions who nevertheless are in very grave situations, and they would wish their life to be ended. I think if that is a rational, autonomous decision then we should respect it.

Mr MULINO — When you use the word ‘condition’ would that include situations, for example, where somebody had a terrible accident and became quadriplegic, which in some jurisdictions is admissible?

Dr HARVEY — Yes, although again a lot of people with quadriplegia can still have fulfilling lives, can still relate to their family and can still, with the aid of devices and computers, communicate appropriately. So again I am not restricting it to a condition. I think it is the effects of a condition in terms of unrelievable suffering which is severe and cannot be controlled. Certainly, quadriplegia does not necessarily fit into that.

Mr MULINO — No, but I am just wondering if that would be allowable if somebody felt intolerable difficulty in coping with it.

Dr HARVEY — I think again there is a need to go through all the safeguards we have talked about — talk to the rehabilitation physicians, talk to the psychiatrists, see if things can be done. Again, this is where I am very supportive of the previous presenter suggesting that all psychosocial and other counselling and therapies need to be involved, but if at the end of the day a person is adamant over a long period of time that their life was really intolerable, and that they did not wish to continue, and that is their autonomous decision and there have been no outside influences in that, then I personally believe that needs to be respected, after due process and on time.

Mr MULINO — If you look at the jurisdictions overseas which have implemented schemes, some recently and some for long periods of time, are there some that you think work well and some not well in terms of the safeguards in particular?

Dr HARVEY — I have read the safeguards. I was impressed with the list of safeguards that the Dying with Dignity Victoria people in their submission put in, which I personally agree with. I am not an expert really on what has happened in individual jurisdictions overseas. All I understand is that I do not think that there has been the expansion of the slippery slope that some people have worried about. That is certainly what I have understood from reading.

Again, I think looking at the most recent Canadian decision, which is a jurisdiction very similar to ours with common-law principles, I think they would not have gone down this path if they also had had grave concerns about slippery slopes and problems. I am the first to say I am not an expert on what is happening in other jurisdictions. I have read some things that said that the concerns about slippery slopes have not materialised, and I know there is conflicting evidence about that, but my own view again is that we should do what is right. The Canadians have decided that this is right for them, and it has been supported by the bulk of the population and there has been very little concern, which surprised me a little, I must confess. I suspect that Victoria would probably react in a similar way since we are a similar common-law jurisdiction.

Ms PATTEN — Just following on a little bit from that, I was wondering if you had any opinion on the Northern Territory legislation on the rights of the terminally ill. There has been some criticism of that, but in my knowledge of it it seems to have quite a few of those same safeguards that, for example, Dying with Dignity had presented.

Dr HARVEY — I think concerns have been expressed that some patients with depression were not adequately treated or diagnosed, that some of doctors involved did not have appropriate training. Again, I am not on top of the actual details, but I think I just reiterate what I said before: what we are talking about is an end resort, after the best palliative care, after the best psychiatric and psychosocial counselling.

If all of that has failed to alleviate unrelievable suffering, then I think physician-assisted death is an appropriate option. Clearly it is something that one needs to make sure that the people signing those certificates and permitting it have had appropriate training, that patients are referred to a psychiatrist. Again, I think a proper referral of those decisions to an appropriate body, be it the coroner or whatever, to ensure that there are no problems is a way of keeping an eye on ensuring that standards are maintained. I would suspect that we would end up, as we have with abortion, with some doctors who have decided that, yes, this is what they will do, and they will do it well. Others will say, ‘No, we do not want to go down this path’, and I respect that. But I do believe that with appropriate training and appropriate referrals, those safeguards should be adequate.

The CHAIR — Just one final question, Doctor, remaining. It has been suggested — we have had some evidence to this effect — that support for voluntary euthanasia is an Anglo-Saxon thing, in a way, and that many CALD communities have a very different view on end-of-life issues. In your experience as a practitioner and, I suppose, that of those who are part of your organisation and perhaps those doctors more broadly who support what you are advocating, would you like to comment on that proposition?

Dr HARVEY — Clearly there are differences in people of different cultures and different religious beliefs in their views on these matters. I respect those, and my colleagues would respect those, but again I just reiterate that I think the views of particular minorities, ethnic communities or religious people should not be imposed upon the majority. That is my belief. I respect those people. I would respect those views and uphold their views. Certainly I no longer practice, but when I was practising those views would be intimately respected, and my own beliefs would never be imposed, but I do not think that people’s strongly held beliefs, either culturally or religiously, should be imposed on everyone.

The CHAIR — Thank you, Doctor. Is there anything before you conclude — anything further you would like to add to what we have discussed?

Dr HARVEY — I would just like to congratulate the committee on going down what is a difficult and controversial path. To me, as I have discussed before, I think this sort of committee work of parliamentarians is remarkably important, and regrettably it does not get publicity, but sometimes the disputes over the dispatch box do. I thank you for your time, and I commend your work.

Witness withdrew.