



LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

(Reference: [Inquiry into end of life choices in the ACT](#))

Members:

MS B CODY (Chair)
MRS V DUNNE (Deputy Chair)
MS T CHEYNE
MRS E KIKKERT
MS C LE COUTEUR

PROOF TRANSCRIPT OF EVIDENCE

CANBERRA

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Secretary to the committee:
Mr A Snedden (Ph: 620 50199)

By authority of the Legislative Assembly for the Australian Capital Territory

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WITNESSES

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Amended 20 May 2013

The committee met at 9.36 am.

OTLOWSKI, PROFESSOR MARGARET

Evidence was given via teleconference.

THE ACTING CHAIR (Mrs Dunne): Good morning, Professor Otlowski. I am Vicki Dunne and I am the Deputy Chair of the Select Committee on End of Life Choices in the ACT. Can I convey the apologies of our chairperson, Ms Cody; she is ill and has no voice.

I would like to declare open this ninth public hearing of the Select Committee on End of Life Choices in the ACT in its inquiry into matters referred to the select committee by the Legislative Assembly on 30 November 2017. The program for today's hearings and the committee's terms of reference are available. The proceedings are being recorded, Professor Otlowski, for the purposes of Hansard, and the hearing is also being broadcast and webstreamed live. I understand that the committee secretary has conveyed to you the privilege statement. Can you acknowledge that you have read and understood the privilege statement.

Prof Otlowski: Yes, indeed. I have received that and I am aware of its contents.

THE ACTING CHAIR: Thank you very much. Do you want to make an opening statement or do you want to go straight to questions?

Prof Otlowski: I would welcome the chance to make a brief opening statement.

THE ACTING CHAIR: Okay. Could you begin by stating your name and position.

Prof Otlowski: Yes. My name is Margaret Otlowski, and the capacity in which I am appearing before this committee is in my role as law professor at the University of Tasmania. Many years ago, in fact, my interest in this area commenced with PhD research, and that was subsequently published as a book, *Voluntary Euthanasia and the Common Law*, by Oxford University Press. Since that time I have remained connected with the issue and strongly believe that we do need reform of the law in Australia.

I would like to point out that in assessing the desirability of legislation we really need to be realistic and accept that it is not a choice of whether we commence the activity of assistance in dying but rather whether we continue to turn a blind eye to a practice that we know does in fact already occur. So really it is a question of: should we be more open and honest in recognising that these practices occur, but in an underground fashion, and endeavour to make these practices safe through regulation?

My real concern is that an unregulated practice, the less safe practice, is less likely to involve consensual assistance, and there is empirical evidence to support that. Even when doctors have, in public statements or in open letters to the editor, indicated their involvement in these practices, there has not been any follow-up or prosecution. Certainly in countries where prosecutions of doctors have occurred they have often

led to not guilty findings because clearly there is not a desire to find doctors guilty of the crime of murder for this kind of compassionate assistance, particularly where it is at the request of a patient.

What I highlight is that the current criminal prohibitions, which do not take account of the intent or the bona fides of the doctor, do not reflect commonly held views of reprehensibility. This is an area where I think, especially for terminally ill patients, there is very little justification for criminal law intervention, and the benefit that could be given by allowing a patient control at their end of life would relieve a lot of angst. It would not necessarily mean that people would avail themselves of it, but it would, I think, be very beneficial.

So I strongly believe that we have more scope to regulate and make space if we are open about practices and services, and doctors can consult peers and so forth. Now that we, around the world, have some examples of legislation in place and empirical evidence to show that it has not led to the alleged slippery slope, I think we would be in a good position to make progress and create safeguards both for patients and for doctors.

Even aside from voluntary euthanasia—and I am aware that for the territory there are perhaps some constitutional constraints—I just want to add that, as the final thing I would say, aside from that active assistance through voluntary euthanasia there are some really important reforms that could be introduced: clarifying that pain-relieving drugs should be regarded as lawful even if they may hasten the death of a patient, and also clarifying that doctors are not under an obligation to provide all manner of care to a person at the end of life and that the withdrawal of care which is futile should not be regarded as illegal.

We have good models. In particular, I draw your attention to the South Australian Consent to Medical Treatment and Palliative Care Act, which makes clear that, where these things are done in accordance with good medical practice, bona fide doctors are free of liability. It just avoids the problem of defensive medical practice if doctors feel that their conduct may be questioned by family or others; that, by actively turning machines off or administering doses of medication for pain relief, they are accused of hastening the death of a patient.

Certainly voluntary euthanasia is my preferred model for assistance in this area. As I say, there are other interim reforms that could go a long way to improving the delivery of end of life care. Thank you.

THE ACTING CHAIR: Thank you. I was remiss before—I should have introduced the other members of the panel who are present. Ms Tara Cheyne and Mrs Elizabeth Kikkert are members of the committee who are also here. Can I turn to you, Ms Cheyne, to see if you have any questions?

MS CHEYNE: Yes, sure. Thanks very much for appearing via phone today, professor. You mentioned that your preference is that we should be not avoiding the fact that this is already happening and that making voluntary assisted dying laws would provide more scope to perhaps regulate and make safe the practices that are already happening. Professor, what are the risks of our not doing that or continuing to

let the situation be as it is into the future?

Prof Otłowski: I think that is a really good question. It is hard to prove what happens underground, simply because it is unregulated, so the scope and extent and nature of it are unknown. But there have been attempts to undertake empirical research. One study I am aware of, which occurred some years ago now, looked at Australia, the UK and the Netherlands and, with similar questions, was inquiring as to instances where assistance had been given that was not explicitly requested.

What was paradoxical was that in countries where you have this very clear prohibition, which one would think would give protection, as in Australia and the UK, there was a higher incidence of unrequested assistance, not necessarily given in bad faith, where perhaps a patient could not indicate their request or perhaps it was the family requesting or other circumstances, than in the Netherlands, where it is an open practice and where they have a lower instance of unrequested assistance.

I am a strong believer in self-determination, and the risk for me is that, where a practice is unregulated and there is not that openness of capacity to discuss and to get the support of peers and advice for the medical profession, they may take things into their own hands. I think the risk is real. The extent of practice that we would not be comfortable with is hard to quantify, but there is no doubt that it is there.

I also think that now we can look to countries like the Netherlands, where they have been performing this for decades. Palliative care is still very strong. I think the concern that if you allow euthanasia then the ability to provide good palliative care will end in fact has been proven not to be the case. You give people the choice and you put people in control, rather than things happening to them as a result of the decisions of others.

MS CHEYNE: I appreciate that. Professor, is making laws for voluntary assisted dying the only way to make things safer or to regulate practices that are already happening or is there another way?

Prof Otłowski: Clearly there are other models. The US model in a couple of states—Oregon and Washington, for example—is the type of model that has been adopted in Victoria, where doctors can prescribe medication for patients to self-administer, with the exception of people who are physically incapable of self-administering, and where the doctor is then permitted to assist. It definitely is progress.

It is a good thing, I think, that that has been introduced in Victoria. But, for me, it is not necessarily the optimal model because it means that, when the patient self-administers, presumably there may be family present but there is not a requirement for the doctor to be present. And in the event that there are complications—for example, regurgitating the substance that is consumed or where it simply is not effective and the patient wakes up—the distress for the patients but also any family members present I think would be extreme.

There are some examples, from Oregon in particular, where they have quite a good mechanism for recording what has occurred. Even though they are relatively few, there are instances where it did not go as planned. I think there are easier ways to

avoid that kind of distress in circumstances where all other areas have been satisfied in terms of eligibility and the appropriateness of the assistance.

I would be concerned for people for whom that does not work in the way it is intended. So I prefer one where there is more involvement of the medical profession. I can see the merit, especially from the profession's perspective, if they want a low level of involvement, that that may provide that. Obviously, you would have to protect doctors from conscientious objection laws and so on so that only those who are willing to be involved would be involved. But my preference remains for a more active level of assistance: encouraging people, where people are able to self-administer, if that is what they want to do, but not limiting the actual active intervention to those who are physically capable, particularly without the protection of a doctor present in the event that things do not go as planned.

MS CHEYNE: Thank you.

THE ACTING CHAIR: Could I just follow up on one of the last comments you made there, Professor Otlowski. You did touch fleetingly on conscientious objection. How would you see the optimal conscientious objection provisions being written into legislation?

Prof Otlowski: Great care needs to be taken with that, in that to preserve the autonomy of a patient it cannot just be closed down: "No, I don't do this," and that is the end of it. Really, as with certain abortion laws, it should be a case of then referring to someone who would be willing to facilitate a patient's self-determination.

THE ACTING CHAIR: So you would say that the patient's self-determination was paramount and that, in the case of a conscientious objector, the conscientious objector would have to then refer to somebody who was not?

Prof Otlowski: Yes. I believe that would be preferable, because otherwise you do not create equality amongst patients. It is the luck of the draw and whether they happen to have someone who is willing to assist or not. I think everyone should have the equal right to access such assistance, if it should become available.

THE ACTING CHAIR: We have heard evidence from the ACT's Human Rights Commission that legislation that compelled conscientious objectors to refer on would itself be an infringement of their rights. How would you respond to that?

Prof Otlowski: There are perhaps other ways in which a mechanism could be created whereby people who are willing to perform euthanasia could be registered and that information could be publicly available so that patients interested in this sort of assistance could access that site, rather than their own doctor having to make the referral, or, at the very least, without naming a doctor, they could say, "There is information that is publicly available," and give them a website where that information can be found. I do appreciate that, for those who feel very strongly about this, they feel that any complicity would be already overstepping the mark. But I think that with some imagination there could be ways around that.

MS CHEYNE: Professor, in your submission you also mention that, while there is quite overwhelming support right across the Australian community for there to be further work and, indeed, legislation on this, there is a lack of representation when it comes to votes in the different parliaments generally. What do you think is the main reason behind this lack of representation?

Prof Otlowski: It is a fascinating question. For me, underlying this is a fundamental question about what a conscience vote means and how that is interpreted in the minds of people. Without going into specific examples, there seems to be voting along party lines, even for a conscience vote, which really undermines what a conscience vote is.

For me, it would be a case of each member of parliament acting on their own conscience, but I think they also should be asking themselves, “What responsibility do I have to the constituents that I represent?” Clearly, if they are following a particular religion that does not allow euthanasia, you would have to respect their decision not to vote in favour of it, but I do think there are some profound questions that can be asked as to what actually a conscience vote means. Is it just the absolute inner thoughts of the person who is casting that vote or do they also have a responsibility to gauge the opinions of the people that they represent, aside from any party political influence that would normally apply in a parliament?

THE ACTING CHAIR: Could I just follow up on that. It seems that the public opinion polls, as Ms Cheyne said, reflect one position and parliamentary votes tend to reflect a more conservative approach. Could that be because public opinion polls are based on one or two simple questions, whereas when legislators actually sit down and look at legislation they might encounter difficulties that the average person is not confronted with when they are asked the question in a poll?

Prof Otlowski: Yes. I am sure that is true. In principle, of course you want to give people autonomy. But then, when you come to craft legislation, it can be very complex to build in a sufficiency of safeguards without overcomplicating legislation. Ironically, in Tasmania when bills have been put forward, part of the reason they have been critiqued is that they are too complex; they go too far in trying to create protections.

No-one pretends that this area is easy, but I think it has been established by other jurisdictions that it can be done. I think that, in general, the public would be very supportive if this form of assistance—whether it is the position of assisted suicide or the more direct form of voluntary euthanasia—were available.

I do not think the uptake would ever be large, but the peace of mind that it would give would be much more significant than the actual instances where it is used in practice: putting people back in control, giving them that sense that they do not have to live out a terrible life to the end, one that no longer meets their expectations of what it is to have a good life. With that irremediable suffering that inevitably occurs: not all suffering can be addressed, and I am sure that health professionals would accept that.

MS CHEYNE: Professor, rereading your submission and taking into account what you have just said, and picking up on Mrs Dunne’s questions before, while public opinion might be a factor in the desirability for some sort of legislation, would it also

then be sensible, if legislation were drafted, to bring the community along with that conversation, through something like an exposure draft, and really talking through all the safeguards that were in it and then gauging opinion again?

Prof Otlowski: Yes. I think this is an area for really engaging with the community, having open forums, giving them a chance to have plenty of feedback into the directions that are being proposed. There will inevitably be groups that are fundamentally opposed. You are never going to be able to please everyone because some hold very deep-seated religious beliefs or beliefs for other reasons that will be diametrically opposed to any form of active assistance.

One of the aspects that I like of the Victorian legislation is that it starts with some principles and this issue of equal respect for every person's life. Clearly, we do not need to be indicating lack of respect by going down this kind of path. I think it is about engaging the community, indicating the intent that it is to assist people and to support autonomy and self-determination and that it in no way indicates a disrespect for life or a desire to push people at the end of life into early termination; it is to do with the quality of living and giving people autonomy so that they are comfortable with the manner in which their life ends.

THE ACTING CHAIR: Could I just go back to some comments that you made in your submission directly about the publication by Alex Schadenberg. You devote a couple of paragraphs to it, but in them you say that he purports to draw a number of findings but draws selectively on particular information, omitting other pertinent information and conclusions that the study authors draw.

Prof Otlowski: Yes.

THE ACTING CHAIR: Could you elaborate on that?

Prof Otlowski: Yes. In fact, I have got some more detailed information about this which I could send in as a supplementary submission.

THE ACTING CHAIR: That would be a useful supplementary submission, if you would not mind.

Prof Otlowski: Yes. I think that would perhaps be the best thing to do. It was drawn to my attention that his book was getting some exposure, which led me to look at the references that he was relying on. Some of them are from refereed publications, but then the quoting is so selective that in some instances the key point of the refereed publication is to say there is no slippery slope but a sentence is taken which would actually give the opposite impression.

It is either very poor writing or a deliberate attempt to mislead. It is concerning, for someone who is a researcher and wants an evidence-based approach and good information to be put out there, to see something that is distorting the truth. That was the concern that I wanted to search there. I would be happy to share with you a more detailed account of some of the information.

THE ACTING CHAIR: I think the committee would welcome that, because the two

paragraphs leave it a bit up in the air.

Prof Otlowski: Yes, it was really—

THE ACTING CHAIR: You have also just made an assertion and there is nothing in the submission to reinforce that.

Prof Otlowski: Yes. I am aware that that may seem to have been done without its own justification, and it was because it was a reduced version of something I submitted elsewhere. I am very happy to substantiate the claim that I make there.

THE ACTING CHAIR: Okay, fine. Thank you.

MS CHEYNE: Just picking up our earlier conversation, professor, about parliamentary representation, you might be aware that next week there is a Senate debate on whether the territories should be allowed to legislate on this matter. We have heard from a variety of people who have put their name on the record, but we have also heard from people in the House of Representatives, including the Prime Minister and some ministers, that they do not support restoring territory rights. Do you have any comment on that?

Prof Otlowski: I find that very disappointing. I see no reason, in the federation, to be differentiating between the rights of states and territories on this kind of matter. I followed the repeal, if you like, or the overriding of the Northern Territory legislation at the time with great disappointment. I just think we need to be more progressive. If it is okay for a state to introduce such legislation, territories should not be in a disadvantaged situation for their populace.

MS CHEYNE: Professor, could you just expand on why you think there is no reason in a federation for territories to be treated differently?

Prof Otlowski: My background is not constitutional law, and obviously we currently do have a differentiation. There is the Australian Capital Territory (Self-Government) Act, and the Northern Territory has its own, so there is a different legal footing. But, as a matter of principle, I see no justification why the way one lives one's end of life should have anything to do with the constitutional basis of the elements of a federation. I think it is inappropriate to be using that commonwealth authority over territories to reach in to areas that deal so intimately with people's lives at the end of life. For me, it just does not sit well not to give each of the Australian jurisdictions the equivalent authority to make these decisions for their own communities.

MS CHEYNE: Thanks very much, professor.

THE ACTING CHAIR: If there are no further questions, we will conclude there. Thank you very much, Professor Otlowski, for your participation on the phone today. You will receive a copy of the proof *Hansard* from Mr Snedden, the committee secretary, and if there are issues that you wish to clarify you can take those up with him. Thank you very much for your participation today.

Prof Otlowski: Thank you.

PROOF

The committee adjourned at 10.05 am.