

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Geelong — 29 July 2015

#### Members

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Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

Ms Fiona Patten

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#### Witness

Dr Neil Orford, Divisional Director, Intensive Care Unit, Barwon Health.

**Necessary corrections to be notified to  
executive officer of committee**

**The CHAIR** — I welcome Dr Neil Orford, the medical director of the intensive care unit at Barwon Health. Dr Orford, thank you for being available to present to us this morning. 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 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 this session this morning, so I invite you to make some opening remarks and after that the committee will have questions.

**Dr ORFORD** — First of all, thank you for letting me appear. I am here as a clinician and as a son. I think that is what grabbed your attention. As a clinician I am the ICU director of Barwon Health. We are referred about 3000 patients a year of whom 600-ish die in the following 12 months. Around 300 would die while they are in our care in intensive care, so my team and I see a lot of end-of-life care.

As a son, which is the reason I think I got your attention — you are aware of my article in the *Age* — I guess my perspective is predominantly around end-of-life carer's spectrum. At one end there is physician-assisted dying and euthanasia, which is a complex ethical and legal area. At the other end, which we deal bit more with, are patients who are at the end of life, and they and their families are not quite ready or prepared for end-of-life care and find it difficult. Sometimes that becomes a legal issue, not often, but the broad majority of this in the middle is about communication, listening to patients and patient-centred care. That is the bit that we are probably not doing so well at in this country — the acute hospital palliative care people aside; they are really good at it.

**The CHAIR** — Thanks for your introductory comments. Perhaps I will ask you, if I could, to follow on from that. How can we do that better? How could the system do communication better?

**Dr ORFORD** — The single step would be to make it a performance indicator for hospitals. We know who is at high risk of dying in the following year. There are good tools out there: there are a number of them, they all work and they are good at helping identify people who are at a high risk of dying. What we do not then do is identify them, go and talk to them, listen to them, give them appropriate advice and then reach a consensus. That is communication.

If we mandated that within 24 or 48 hours of being admitted to an acute hospital you had to have a patient-centred discussion and have a document about what you wanted, it would change behaviour. It would change all sorts of behaviour because we would have to then teach doctors how to communicate and put in systems to help identify people. I suppose in my experience recently with my father, that is what we wanted. We wanted someone to come to us on the first day. We were not looking for people on the first day, but we wanted someone to say to us, 'You guys are in trouble as a family. Your father is demented and dying. He will die in the next year. What do you want to do?'. We are not saying we should have end-of-life care decisions forced upon us, but we should talk to these people and listen to them. That is what we do not do well. It has to be timely.

**The CHAIR** — Yes. As a follow-on question, if you look at a system-wide perspective, based on what you have just said, ideally with an admission to a hospital you would have that directive within 24 or 48 hours. However, we have heard others say that ideally the system would work to identify individual choices and preferences earlier.

**Dr ORFORD** — I would have a three-step response. One is community-based conversations, particularly around these people who we know are at a high risk of dying in the next year or who are in their last year of life. With the Respecting Patient Choices plan and advance care programs — that community-based model — you still need to talk to them when they hit the door of an acute institution. It is a bit like organ donation where we know that if you talk to people in the community, understand them and get the conversation going, they will think about it. They may have some pretty strong feelings. When you hit them at an acute hospital, it is very hard to predict all the scenarios, so you still need to be talked to then.

It is not too late. It would be better if everything was set up earlier. There is evidence around this. People are prepared to talk about their end-of-life care as they are deteriorating and dying, because they have got skin in the

game. It matters and they want to talk about it. It is not overly distressing for them. Our experience and the experience that is published is that they welcome it. I would have it in the community within the first one or two days — if you are going to be soft, you would say two days because it covers weekends — but within the first working day of hitting the hospital, and then again as people are deteriorating and dying in the last days of life, that sort of process again, just to make sure you have got it right.

**Ms PATTEN** — It was remarkable what your story in the *Age* generated. The volume of comments that it generated was quite extraordinary, and I found it great that this inquiry is obviously very timely, considering the outpouring that your story gave us. I think you are absolutely right as to if we can somehow mandate these conversations, and that is coming up time and time again. I suppose I am still looking towards that other end of the spectrum or the toolbox of physician-assisted dying. Looking at the responses to your story, that was what a lot of people were focusing on and that was not relevant to your particular story necessarily. So we had this thing about the double effect of maybe hastening death but doing that to comfort the patient, or being more proactive. Do you think we are in that space to be more proactive?

**Dr ORFORD** — Do I think we as a society — —

**Ms PATTEN** — Yes. We might never need it, but yes.

**Dr ORFORD** — From the feedback that you get from the submissions you have here, it would appear we are, but certainly there is a debate that has to be had. There was an article in the *Economist* about a month ago talking about physician-assisted dying and suggesting that in countries where it has happened — and there are a lot of countries, a lot of experience — that it has improved palliative care in those countries because if the physicians involved have to discuss physician-assisted dying they have to become very good at discussing palliative care. Although I personally have reservations, because I am so consumed with getting the middle bit right, clearly society wants to talk about it in a sort of open, hopefully mature way. Certainly I think society wants to debate it. Yesterday on the Jon Faine program there was an entire session talking about this, and most of the talkback was about having the opportunity for physician-assisted dying. Although personally I do not particularly want to go there, it clearly resonates with the community.

**Mr MELHEM** — So what would you change in your dad's experience? We have already talked about that a bit, but specifically. If now you have got, let us say, an open book and say, 'Okay, let's go rewrite what happened and how we'd handle it differently and what changes to the system we can approve to make life easy or the end-of-life process easy for you, the family and the patient'. So you are going to rewrite history and improve it.

**Dr ORFORD** — I would have a system in a hospital that used a tool, and all tools that look at post-care needs include advanced dementia as a trigger or a criterion to identify. So I would have a tool that identified people like my dad in the first day they are admitted to hospital. I will say he was not admitted to a hospital in Geelong, so you are off the hook! But then I would get someone, a trained person, to go and talk to the family and the patient about what they want. That is the first step.

So if someone had approached us — and they did not have to, as we were looking for people, but that is just because we were advocating fairly strongly — and said, 'Your father has got advanced dementia. He's probably in the last year of his life. He's now got a bleed in his brain. He's confused, distressed. You all look really distressed. Can we talk?', everything would have just gone from there. And then you would have systems of saying, 'If you want treatment limitations, what sort of care do you want?'. I would have a system that identifies you first and quickly, has a skilled communicator talk to you and then a process behind that that puts in place what you want, be it if you want full intervention, if you want middle-of-the-road, if you want a very comfort-care, palliative-care pathway. They are all ways of caring, but until we ask people we cannot give it to them. It is not hard. Communication is hard. Teaching people how to communicate is a commitment that takes time.

**Mr MELHEM** — In your dad's case the trigger was the fall, or it was for the first one, and then it was sort of traumatic. I am just going to give another example. I think it was in the local paper that Rod Mackenzie, a former member of Parliament, was talking about his dad. It is not as traumatic — I am talking about his dad's dementia — but he is confined to bed, he is not mobile anymore, not aware of anything. Possibly he is comfortable, but he is talking about loss of dignity and everything else. What do you do in those circumstances?

Do we go as far as saying assisted euthanasia is an option? Do we go that far, or do we say he is comfortable? What do you do in that situation? I know it is a very difficult one because of what he went through, plus your position as a doctor as well.

**Dr ORFORD** — I would just go back to being — patient centred is what we are trying to change to. If he is comfortable in a nursing home, ideally we would have good community-based end-of-life care where we would go and talk to them. Their GP, the Respecting Patient Choices team, whoever, the trained people — so, as the previous people said, be approaching with a sort of tick-box menu. Do you want end-of-life care? Do you want CPR? Do you want to live on the moon? Do you want to be 30 years younger? All of those things.

**Mr MELHEM** — I like the last one!

**Dr ORFORD** — That is right, but you cannot have it. You need to offer them reasonable advice and you need to listen to what they want. That can happen anywhere. The majority of people with advanced dementia say, ‘I would like dignity’, or the next of kin say, ‘I want dignity’, it may well be that you choose then to be cared for at home or in the nursing home with supports and be kept comfortable as you deteriorate with whatever comfort measures. Whether that extends into assisted dying is important. It needs to be debated, and how I feel about it is probably not the issue because there is a whole range of palliative care needs that we are not meeting and that little bit — or that big bit for a lot of people, and certainly again that article in the *Economist* says if you offer it, people love the comfort of having it and knowing that they might be able to use it if they need it, even though many do not. But I think that bit of the debate is not my area of expertise, and the rest would change society if you were to offer patient-centred care to everyone.

**Ms SYMES** — Thank you for sharing your story. I think a lot of people have gone through similar circumstances. I am interested in your suggestion that you could have the conversation at the hospital. What is your experience of people having that conversation? You were able to articulate that for your family comfort was more important than cure in this situation. Is it difficult for people to come to that conclusion at that early point in time? I think it is one of those things that in hindsight everyone would go, ‘Yeah, that would’ve been better’. But where is the community mindset?

**Dr ORFORD** — It was difficult for us. It sounds like I did it really well and then I wrote it down but it was, you know, a teary, drawn-out process. It is difficult for families. We have a lot of end-of-life conversations in hospital as intensivists and as physicians, but I have almost uniformly and my colleagues had a — positive experience is not quite right because there are some, there is a very small group, a minority of people, who are life at all costs and who will say, ‘We don’t want to discuss it’, but even they are prepared to have the conversation because then they get to say, ‘These are my views. This is what matters to me. I am life at all costs. I want to die on a ventilator’. So having that conversation is well accepted.

The barrier, I think, is that as clinicians, if you are not experienced at it and you have not been taught or witnessed it, you think that it is going to create tension and anger and distress, but it does not. If you do it well, most people welcome the opportunity, if it is done well, and they find it a great chance to say what matters to them, what matters to this person in the bed. It would be better if they were ready for it. Again, the organ donation analogy is really good: it is an easier conversation to start if they have considered it.

As a society, up until now, we do not really talk about death that much. It is not in our media; it is not on our television. Everyone survives cardiac arrests in soap operas. But I think people are prepared to talk about it if it is done sensitively. But that is the challenge. It is easier just to go up to them and say, as they did to my dad, ‘You had a fall. Let us not even talk about the dementia. You have got a brain injury that will probably get better over two weeks in hospital. We will do these things to treat you and leave it at that’. But if you sit and ask people about what matters, they often welcome the opportunity to tell you about all these other things that are worrying them. They do not have to be articulate; you just have to listen to them and ask probing questions.

**Ms PATTEN** — Last week we heard evidence, again talking about the double effect, and we heard in one circumstance where nurses were very nervous about providing adequate pain relief for fear that it would hasten death. Those nurses felt that — I think it was particularly overnight and in those early hours of the morning — that was a problem. The professor that we spoke to suggested what he called an elegant response to this, which was to provide a defence to any medical practitioner that was providing medication to a terminally ill person,

that it was a defence if it was for comfort even though it did hasten death. Is that something that concerns you or that you think is necessary in terms of the practices we are using today?

**Dr ORFORD** — Can I ask out of interest, were they ward or ICU nurses?

**Ms PATTEN** — This was ICU nurses, or was it palliative care?

**Ms SYMES** — Palliative care.

**Ms PATTEN** — It was palliative care nurses actually, sorry.

**Dr ORFORD** — Yes, it concerns me. No, I do not worry about it. Like at the start when I said there are two ends to the spectrum: there is the physician-assisted dying bit and the withholding/withdrawing life-sustaining therapies in the intensive care end, which is us. Of the 200 deaths a year that happen in our intensive care unit or around it, the vast majority are planned. They move from life-sustaining therapies to palliative care. Our intention is comfort, so I do not worry about it. We have protocols in place; we have a workforce that is clear. We do get asked occasionally if we can move from — —

We say we are giving morphine and other agents to ensure someone is comfortable, because one of the biggest fears that every family has when we change to palliative care is that, 'My loved one is going to suffer'. That is a universal fear. So we go to a lot of effort so they will not and institute comfort care. Most of the time people are happy with that. Every now and then someone says, 'Can you make it quicker?'. And we say, 'Our intention has to be comfort'. So again I am sure that it is an area that if it became legal, we would see more of it. I do not worry about us being prosecuted for assisting dying because we are pretty clear that we do not. We have got with our palliative care team very clear protocols to say what the appropriate doses, measures and documentation are. So no, I do not think we need anything to change.

**The CHAIR** — Doctor, if I could take you back to your introductory statement, you talked about the number of patients you see through the ICU on an annual basis — about 3000 a year, and of those 600 die within 12 months and 300 die in the ICU. Are those 300 admitted and they basically die?

**Dr ORFORD** — Three thousand get referred to the ICU. We admit about 1500, of which about 150 to 200 would die in the ICU. Of the 3000 patients referred to us, 1500 do not get admitted either because they do not need to be or because they have got end-of-life care needs and do not want to be. Of that cohort of 3000, about 10 per cent die in hospital.

**The CHAIR** — Of those people, do many of them come in basically without having had that discussion previously or without any sort of documentation about their wishes?

**Dr ORFORD** — Most of them.

**The CHAIR** — It must be very challenging for you and your colleagues.

**Dr ORFORD** — It is. If you in talk to intensivists in my ICU, in the country, or if you go to intensive care conferences internationally, a clearly recognised concern and worry on our horizon is the increasing demand for end-of-life care. That is not quite right — it is that we are seeing patients who are dying and who are not ready for it, and as a result we are probably providing care that does not meet their wishes because they have not been established. And that is in the UK, Canada, the US and us; it is a very clear message. We have looked at thousands of patients referred to us, and maybe only a quarter of those who are going to die in the next year have clear evidence of a patient-centred discussion. I say patient centred because quite a few people have a tick box saying, 'I want everything' or, 'I don't want everything', but if we are going to do it well, we will ask them what matters to them and what they want in the next year. We will have those sorts of goals of care discussions with them. No, we are not doing well. No-one is doing well as far as I can see.

**Ms FITZHERBERT** — Firstly, thank you for being prepared to speak about some very personal events in your life. That is very generous of you. I wanted to ask you about one aspect of that if you do not mind. I was interested that in your article you said that you asked daily for a referral to a palliative care team but that just did not happen — it took more than a week. What happened? Were people not hearing you, were they refusing?

**Dr ORFORD** — Yes.

**Ms FITZHERBERT** — Why was it not working?

**Dr ORFORD** — I do not know. I am sorry. It was quite frustrating. I got away without answering any personal questions until now.

**Ms FITZHERBERT** — I am so sorry. I did not want to upset you.

**Dr ORFORD** — Look, I think it was the system in that hospital. They have a palliative care team in that hospital. I think it was that they did not have a system. To be honest, I have no idea. It is incomprehensible to me that that can happen. I deliberately was trying not to say, 'Look, I am an intensive care specialist'. On the first day — it was a Saturday — and we said, 'Can we just talk end-of-life care?'. We were being really nice and engaging, 'We do not want Dad to have blah, blah, blah'. I was told that we would not be able to speak to a clinician until the Monday, and if he deteriorated, he would have CPR.

**Ms FITZHERBERT** — Quite counter to what you were saying?

**Dr ORFORD** — Yeah. And it was quite distressing for the family, so we got angry. I am sure we looked like this difficult family of angry professionals who were spoilt, but what do you do? And then on the Monday we did meet a care coordinator who was lovely. We thought, 'Great, that is it', but then it took another week. It was in Queensland, so I had to come back and go to work and then went back, and my mother was left feeling very guilty, because if you ask every day for palliative care and do not get it, the implication is that you are trying to kill your husband and that you are wrong. And so that was very, very difficult. I do not know. I do not understand how it can happen.

**Ms FITZHERBERT** — Thank you for the answer. I am sorry to raise issues that are obviously very distressing. I apologise.

**The CHAIR** — Dr Orford, thank you so much for not just your, as Ms Fitzherbert said, particular skill that you can tell us about from your own experiences but for you to share such a personal story is deeply appreciated.

**Dr ORFORD** — Thank you.

**Witness withdrew.**