

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Traralgon — 9 September 2015

#### Members

Mr Edward O'Donohue — Chair

Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

Ms Fiona Patten

Ms Margaret Fitzherbert

Mrs Inga Peulich

Mr Cesar Melhem

Ms Jaclyn Symes

#### Participating Members

Mr Gordon Rich-Phillips

#### Staff

Secretary: Ms Lilian Topic

#### Witness

Dr Brian McDonald, Clinical Director, Palliative Care; Clinical Practice Group; and Consultant, Gippsland Region Palliative Care Consortium, Peninsula Health.

**The CHAIR** — I welcome Dr Brian McDonald, the clinical director of palliative care; clinical practice group; and consultant at Gippsland Region Palliative Care Consortium, part of Peninsula Health. Dr McDonald, thank you very much for joining us this morning. Before we start I will 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 the proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website.

We have allowed half an hour for this session this morning, so I invite you to make some opening remarks, and thereafter the committee will have questions. Thanks again for being here this morning.

**Dr McDONALD** — I am assuming my invitation to attend here was because of my connections with the Bass Coast and the Gippsland regions?

**The CHAIR** — Yes.

**Dr McDONALD** — So in terms of our role, and I say 'our' role because it is part of the Peninsula Health palliative care team extension, we have been coming down to Gippsland — initially Bass Coast and South Gippsland — for about nine years. We have increased, by invitation, our activities from one visit a month to four visits a month. The visits now, as of 18 months ago, include a palliative medicine physician — either myself or one of two colleagues — and in recent times we have a counsellor and a social worker who comes on the same visit. Once a month we go to a base in Leongatha and then extend to Foster, another once a month we go to Korumburra, once a month it is Wonthaggi and the last monthly visit we go to San Remo and Phillip Island.

The way we operate in general is that we meet with the palliative nurses and allied health, which might include physiotherapists, occupational therapists and social worker/councillors, and we will often go through the patients who are listed with the palliative care service and have a discussion, sometimes very brief, sometimes a bit more in depth, in terms of the, I guess, holistic care which is being provided and how it is being provided. As a doctor our focus is often around symptom management. We provide advice in terms of symptom management, particularly complex symptom management. When we meet in Foster, Korumburra and not so much San Remo but Phillip Island, there are often local medical practitioners who come along. It is basically an open agenda, and they come along to discuss individual cases and just to have a conversation in general. We try to provide the service which the local services want us to, and it seems to work.

**The CHAIR** — Great. Thank you very much for that. By way of the first question I will ask: from what you have said, you are seeing an increase in demand as time goes on in the 9 or 10 years Peninsula Health has been providing services into that South Gippsland and Bass Coast region?

**Dr McDONALD** — I do not know what the statistics are, but in terms of the demand, the demand seems to be from the current local providers. The value of what we do? We ask the question quite commonly, 'Is it useful us coming down once a week overall?', and the answer has always been, 'Yes, we wish we could have more'. We also provide telephone support to both the particular district nurses and to the GPs. It is not uncommon — it does not happen every day, but it is not uncommon — for GPs to phone just to discuss cases. Occasionally, if there is a patient in the Gippsland region with complex care needs and with complex symptom management needs in particular, we will arrange for them to come to the palliative care inpatient unit at Peninsula Health in Frankston.

**Ms PATTEN** — My first question is: in a lot of the evidence and submissions we have received there is a real concern about doctors' ability to communicate around end-of-life conversations. I think you heard the previous submissions. Would you concur with that? I guess because you are seeing a lot of GPs and you are talking about palliative care, is this something that you are concerned about as well?

**Dr McDONALD** — In a previous life I was in general practice — many years ago now. My observation would be that at general practitioner level the communication is usually quite good. There is so much variability in terms of communication from other specialists. I would rate oncologists as being relatively good, but again it is very variable. It is a challenging area. I think most of my medical colleagues do reasonably well. I would like to see more of them attend specific educational opportunities such as breaking bad news; that is taught to

undergraduates now, and there are courses often available for more senior physicians and physicians in training. I think it is probably improving. But, yes, it can always improve further.

**Ms SPRINGLE** — There is obviously a big increase in demand for your services, but who are the people that you are actually servicing? Are they people in the home, or are they in facilities?

**Dr McDONALD** — Most of the time I would say we are servicing the care providers by providing additional support. We are hopefully reinforcing what they are doing, and they are the messages we are getting. We do, on request, see patients, sometimes in the home, sometimes in the hospitals. Sometimes our counsellor will disappear for an hour to speak to families, both in terms of, I guess, preparing for death and also during a bereavement phase. Clearly she cannot follow through, but she will have conversations with local counselling supports. They tend mainly to be social workers. Occasionally we are lucky enough to have a psychologist, but they are fairly few and far between.

We recognise, and have done for many, many years — which I think is why not just Peninsula Health but other health services are outreaching to rural communities — that resources are very limited and restricted and we have had to adapt and work out what the local resources can do and how they do it. Overall I think they do a fantastic job, but getting a little bit of help from those of us who are in specialist practice seems to be beneficial.

**Ms SPRINGLE** — In your view do you think it is an issue of resourcing, or do you think there is room for law reform around end-of-life choices?

**Dr McDONALD** — The end-of-life choices is another issue. That has come about from Respecting Patient Choices programs and the interest and acknowledgement that people should — I do not know about ‘should’; ‘should’ is strong — they may choose to make decisions in terms of what treatments they might want if various conditions arise. One of the challenges of end-of-life choices is that none of us really know what our choices are going to be until it happens. We can have conversations. Certainly at home we think we know what each of us needs, but until it happens we do not really know what our decision is going to be.

But having the documented end-of-life choices program makes it a little bit easier when people present with life-threatening situations. Again, I do not know what end-of-life choices programs are available in the Gippsland region, but certainly we are lucky at Peninsula Health. We have funded staff whose specific job is to look at end-of-life choices and go and interview and clarify and work with patients — or probably clients — who request assistance, at home, within the hospital, within the health service and within the aged-care facilities, so it is slowly but progressively evolving. I think it is very useful, and as I am sure you have already been made aware of there are lots of programs to reduce inappropriate hospital admissions. There are outreach programs to residential aged-care facilities in most of the metropolitan health services to support the residential aged-care facilities and the Respecting Patient Choices program is developing.

**Ms SPRINGLE** — Do you provide support to aged-care facilities or is it just hospitals and medical facilities?

**Dr McDONALD** — Part of my role and part of the role of Peninsula Health palliative care program includes providing medical consultancy support for the Peninsula Home Hospice service, which is the home hospice service for the Frankston Peninsula region. They provide some nurse consultancy support to residential aged-care services. General practitioners will sometimes invite us to assess a patient. Again, it is on an individual basis. As part of the Peninsula Home Hospice, yes, we are involved. But as recently as last week a local general practitioner asked me to speak to the wife of a severely disabled, acquired brain injury patient, and I had a conversation. We discussed the options. She then goes back to the general practitioner who is looking after the patient, who is able to then have a conversation with a second opinion. I have not taken over her care; I have not taken over her management. A lot of GPs find that useful.

**Mr MELHEM** — I think you have answered my question partly, but I will ask it. Do you think Victorians are aware of their end-of-life choices, particularly in this region, and if not, what do you think we should do to change that?

**Dr McDONALD** — It is extremely difficult for a patient or family to say, ‘Stop’. It is extremely difficult unless they are presented with the options. Most patients, say, for instance, if an oncologist or a cardiologist is talking to them and there is a treatment option, in my opinion, will say, ‘I’ll have that’. We can fix lots of things.

Although it might sound like, ‘Is it worthwhile having chemotherapy to prolong my life by two or three months’, when you are talking about it hypothetically it is a really easy answer: ‘No, I don’t think it’s worthwhile’. But when you are actually being offered treatment which might prolong your life for a few weeks or a few months, and sometimes much longer of course, then most people will say, ‘Yes please’. So it is so subjective, and it is so individual. Families spend tens of thousands of dollars on what might be regarded by some, and it is just not necessarily by me, as futile treatment. I have seen families cash in superannuation to pay for chemotherapy, which might have prolonged a daughter’s life by a few weeks, a few months. It resolves the hole and it just keeps people going. Now we have to recognise that.

One of the shifts — I am not even convinced it is a shift — but one of the things that happens is that yesterday I saw three patients at the request of oncologists and haematologists who were working together. There is a lot more — and I would like to see probably more of this — of palliative care and oncology and cardiology and neurology working together. The oncologist continues with their treatments. I am in yesterday evening for a conversation. It did not change any medication, but it was just to provide that perspective for the patients and the families in terms of what the options are. I had to have two conversations in a private hospital yesterday evening with patients I had never met before. One of them, ‘I’ve had enough. Let nature take its course’, and the other, ‘I need to keep going with the chemotherapy’. I had no idea what I was walking into, but it just emphasises how individual it has to be. But yes, I think that what we have been trying to encourage — and we are very well received by most of the acute care physicians, whether it is oncologists or cardiologists or whoever — that dialogue, including palliative care, whether it is palliative care or palliative medicine. Palliative medicine is a little bit more specific, and although we must have a holistic approach to the care, we are probably used more for our expertise and symptom management.

**Mrs PEULICH** — Doctor, I was going to ask you two questions but I will ask you one. It seems to me that the call for a more robust regime for end-of-life care — subtext euthanasia — often comes from people who may not necessarily be going through those critical choices at that point in time. Just a personal anecdote; I was sitting in a cafe, talking to a fascinating woman who was in her 90s, who had lived in India, who was vibrant, interesting. Her family had taken her out for lunch at the local cafe from a nursing home. We chatted, and as she walked out — and she was quite stylish — her daughter-in-law turned around and said to me, ‘I wouldn’t want to live that old’. To what extent are those who are calling for a more robust end-of-life regime, code for euthanasia, bringing a different perspective to those who are actually faced with death? Let me just clarify. There was another member of Parliament who was a strident campaigner for euthanasia. He had seen his sister die a death, and I cannot really exactly what the conditions were. His sister was a strident opponent of euthanasia. Yet he felt that notwithstanding that, that her life should have been ended early. Are you able to comment?

**Dr McDONALD** — The euthanasia discussion has been going on for 30 years and more. We all know that 75, 80 per cent of the population will say ‘yes’ when asked a question: ‘If someone is in great pain and suffering and is dying, should a doctor be allowed to administer a drug to hasten the death?’ — euthanasia. Life is not that simple. I often see patients well before the terminal phase of an illness. I will give them a commitment that when they are dying, if there is significant distress, I will do all that I need to to relieve that distress.

Often I will say, ‘If I have to anaesthetise you and allow you to die, that is the extent to which I am prepared to go’. I do not think that I could practice my profession, practice my craft, unless I was prepared and able to do that, and I can and I do. Not very often, maybe once or twice a year, I will need to resort to using literally an anaesthetic agent. We do provide terminal sedation quite frequently, where we render the patients unconscious. I talk to families, and I will talk to the patient if they are aware enough to talk to, because people seem to understand the medically induced coma. I try not to beat about the bush and pretend. I try to be upfront and straightforward and say, ‘If you want sedation, if you need sedation for maintaining your comfort, that is what we will do’. Irene earlier mentioned existential angst. That is something, and this is where Rodney Syme and his colleagues will say, ‘We’re not terribly good at that, and we do not have a good answer for that’. Occasionally we will relieve existential angst using terminal sedation because the person is suffering and that is to say the word. At the end of the day people do not want to suffer.

**Mrs PEULICH** — In this modern age should anyone be dying suffering with unmanageable pain?

**Dr McDONALD** — What I say to patients, what I say to families is, ‘If suffering is part of your dying process, then I’m not doing my job properly or you’re not letting me’. People are entitled to say no. They do not

often do so because they put an enormous trust in doctors like me — it is quite scary. As part of the communication, how you put it across, because in this day and age we have a focus, quite rightly so, on patient autonomy, patient choices, informed choice, informed decisions, but the bottom line is, not uncommonly, ‘Doctor, don’t ask me. You know best’. As I say, you have to take into consideration everything that you are picking up from the patient, everything you are picking up from family members, and the bottom line is it is a judgement call around the time.

**Ms PATTEN** — Following on a little bit from Mrs Peulich, we have certainly received a lot of submissions that commend the palliative care that we have today, and I think we do have some world-class practices, and we are starting to treat it as a very serious medicine. However, there are people who say, ‘I still want to have the right, the last decision about when I think there has been enough’. I know it is very often an existential decision. Without our patient autonomy and our respect for those decisions, we respect their right to refuse treatments.

**Dr McDONALD** — Yes.

**Ms PATTEN** — Do you think that we could legislate to respect their right to be more proactive in that choice?

**Dr McDONALD** — Personally, yes I do. I used to do a lot of work with patients with AIDS when AIDS was a terminal illness.

**Ms PATTEN** — I remember it well.

**Dr McDONALD** — I am aware, I would say, of at least four patients, with whom I was involved, who accessed euthanasia from doctors who were prepared to provide it. I could not make any judgement on them, but that was their choice, that was their decision, and resulted from this professional relationship, albeit sometimes very short, with a doctor. It had all been determined by psychiatrists, and none of them were mad; none of them had a severe treatable depressive illness. They were all dying.

That has been going on forever. It is not publicised, it is not out in the public arena particularly. But there was a survey done — I think it was in the 1990s — by Peter Singer, Helga Kuhse and so on. It was published in, I think it was, the *Medical Journal of Australia*, and 2 per cent of all deaths in Australia were calculated as the result of euthanasia, which at the time was the same as the rate in Holland. I think it is important in the discussion. It is not me that makes the choice — it is you guys. In Parliament you will make choices in terms of whether euthanasia laws are changed or not. From my observation over the years, whether it is the UK, whether it is Australia, there has been lots of consideration of changing laws to decriminalise euthanasia, and my understanding is that the main block tends to be the slippery slope argument. There are others much more qualified than I am to comment on that.

**Ms PATTEN** — But as a doctor, do you believe there would be a slippery slope?

**Dr McDONALD** — Probably not. Palliative care as an organisation, as a movement, I guess separates what we do in palliative care and palliative medicine from part of the conversation around euthanasia. Many palliative care clinicians, nurses and doctors would say, ‘Well, it is not something which is appropriate to be provided in a palliative care setting’. I am not sure about that.

**Ms PATTEN** — I know. We have got terminal sedation.

**Dr McDONALD** — Yes. Often the argument in terms of what I do and with terminal sedation is: what is the difference? I have been commenting for many years that there is a difference, but is it a big difference? Occasionally we will still hear the expression ‘slow euthanasia’, so ‘isolate patients, allow them to die’. If we do not provide them with nutrition and hydration, we know they will die.

Another comment I sometimes make is that I wonder how many of the families who walk out of the inpatient unit think that we have provided euthanasia. I think it is probably quite a substantial number: ‘making them comfortable’ may be interpreted by the family as basically saying that is euthanasia. I do not believe it is from a legal perspective, and from a medical ethics perspective it is not. We are providing symptom management, we are providing relief from distress and that at the moment is our mission in life. If euthanasia were legal, would I do it? I do not know. It is hypothetical. I do not know.

**Ms PATTEN** — Of course. Thank you.

**The CHAIR** — Thank you, Doctor, very much for your presentation and your preparedness to answer questions in such an honest and frank way. We really appreciate it. As I said at the start, you will be provided with a proof version of the transcript shortly, and ultimately that will be made public. Thank you again for being here with us today.

**Dr McDONALD** — Thank you. Thanks for the opportunity.

**Witness withdrew.**