TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 18 November 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

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Dr Grant Davies, health services commissioner, Office of the Health Services Commissioner.

The CHAIR — I would now like to welcome Dr Grant Davies, the health services commissioner. Dr Davies, I would like to thank you for being with us today and also note that the committee has received and read your submissions, so thank you very much for that. Before I ask you to make some opening remarks 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 a proof version in the next week or so, and transcripts will ultimately be made public and posted on the committee's website. We have allowed half an hour for our time today. We would like to thank you for being here and invite you to make some opening remarks or an opening submission, and after that the committee will have questions.

Dr DAVIES — Thank you very much. I appreciate the opportunity to provide some testimony here today. It is worth noting that I have a palliative care nursing background, so I just want to put that on the table for the committee. You have read my submission; I do not intend to go through that in detail. I just wanted to raise some headline points in my opening remarks.

Poor communication plays a significant part in the difficulties in end-of-life care. There is a reluctance to talk about dying, and that is not just in terms of clinicians; I think sometimes consumers, patients, are reluctant to talk about their dying as well. It is a highly emotive time for relatives and carers, which makes communication difficult right from the start both in relating to clinical teams and in the communication process between them.

I think transfer to alternative care is also problematic. Demand is outstripping supply of inpatient palliative care, necessitating the need to transfer into other residential care. Often it is residential aged care, which is not an environment really geared towards what can be highly demanding care needs at the end of life. Transfer of young people into residential aged-care facilities is also very problematic.

Entry criteria into inpatient palliative care due to high demand are getting higher, and this creates a burden on relatives and carers. I have spoken to a number of relatives and carers who are really stressed about trying to get some inpatient palliative care needs met. Linked with that is the availability of community-based palliative care. The availability and quality of that care is variable across the state. Interestingly, Nikki McCaffrey in the online journal the *Conversation* yesterday quoted figures that stated that in 2011 and 2012 just over half of Australians who died died in hospital, despite a majority of people wishing to die at home.

Some of the recommendations that I would make in relation to mitigating some of these issues would include better training throughout a clinician's career on good communication and the process of end-of-life care and in particular in CALD communities. I think they are particular challenges, not just in terms of language and understanding but also in terms of cultural needs. I know that some cultures, for example, do not talk about dying, do not want to talk about dying, do not want to acknowledge dying, so that can be very difficult in a care setting. I know Palliative Care Victoria has run some workshops in 10 communities, and they have highlighted this need.

Alternatives should be found to transferring people at the end of their life to residential aged-care facilities. As I said, it is not appropriate. Standardised entry into inpatient palliative care services should be established. I think as demand increases the availability will become increasingly difficult. Of course greater availability of inpatient palliative care is important. Equity of access and greater availability to high-quality community-based palliative care is important as well. Finally, I think legislating for advance care plans would be an important part of this process.

The CHAIR — Thank you, Dr Davies, for those opening remarks. I am just interested from a practical perspective in the sorts of complaints you received and talked about in your submission as well. You talked about poor communication. I note that alternative dispute resolution is the preferred model to resolve disputes that come to you. Do you find that once issues are clarified between parties often people walk away thinking, 'How did we get to this point?' — that sort of thing? I am just interested in your perspective on the complaints you receive.

Dr DAVIES — Most of our complaints have a miscommunication or poor communication that underpins them. Really that is a clash of people's values. I think if we are serious about person-centred care, end-of-life care is where the rubber hits the road in terms of that approach.

Let me give you a personal example. My sister died a couple of years ago, and my mother was in the room with me with the palliative care GP. This was in Queensland, so it is not in Victoria. The palliative care GP was very clear about what palliative care was about and how the process would go. Once my sister, Sarah, had died, my mother said, 'If I had known what palliative care was about, I would never have agreed to it'.

As I said, because of the highly emotive nature of this space it is very difficult to communicate in this area. It requires specific skills. Once we see complaints about this sometimes we are not able to resolve those complaints for people. They are so entrenched, and grief is a very difficult aspect of our complaints resolution process. Grief complaints are very difficult to resolve, so sometimes we do not. That is unfortunate, and we see that as not being ideal.

Ms SPRINGLE — What would be your practical recommendations to improve how these issues are overcome and how communication can be improved?

Dr DAVIES — Communication skills both at undergraduate and postgraduate and as part of CPD, or continuing professional development, in the education of all clinicians is critical. I do not know whether you are aware of Bob Arnold. Bob Arnold is an oncologist from the United States, and he talks about what good communication looks like. One of the things he talks about is an ask-tell-ask process: you ask the person what they understand about what is happening, you tell them what is happening and then you ask them again what they understand you have just said.

Lots of clinicians do the first two things but do not do the last ask, and that is where the point of difficulty arises. There is not the checking in and clarifying by which people really understand what has been told to them. Certainly that sort of process in a continuous way throughout people's careers would be really important.

Ms PATTEN — We were just hearing from previous speakers about medical power of attorney and where that sits with other family members and the power. Would you support the idea that a medical power of attorney would have power over all decisions at end of life or that an end-of-life care plan that a patient has developed would override the medical power of attorney?

Dr DAVIES — That is a tricky space. If someone has made their wishes known when they are competent and have the capacity to do so, that should take primacy, rather than having another person who does not necessarily know. They might have a pretty good idea what people want, but they do not actually know if they are not able to check with them. It is a bit outside my area of expertise, but in my view people's autonomy should be respected.

Ms PATTEN — Is that a complaint that has come across your desk — that a patient had certain wishes and the family had other ideas and that was where a dispute emerged?

Dr DAVIES — It is more likely to be the other way around. It is more likely to be the family asserting that the person has this set of wishes. There is no way to check that, so it is hard to say whether that is the case, because people rarely express a view other than to their family members of what it is they want at the end of their life.

Mr MELHEM — Do you think the current level of funding in Victoria is adequate to address the issue of end-of-life palliative care, and how do we compare with other states?

Dr DAVIES — Mr Melhem, I can only go on what sorts of complaints I see. I get complaints about a lack of high-quality palliative care in the community, and I get complaints about being asked to transfer out of inpatient palliative care and difficulty getting into palliative care. Whether that funding arrangement is adequate is not something that I am qualified to talk on.

Mr MELHEM — I appreciate that. The reason I ask is because I have picked up on some of the issues you have raised. From your point of view then, what changes would you like to see to improve the current situation?

Dr DAVIES — The availability of inpatient palliative care with a standardised set of entry criteria would be critical. Having a consistent quality and availability of community-based palliative care across the state is critical, and a seamless transfer between those two environments would be important as well.

Mr MELHEM — I notice you talked about the after-hours response — for example, general practitioners attending to aged-care centres. What can we do to improve that situation? Do we look at paying doctors more, for example, to come in and attend after hours? What other changes can you think of?

Dr DAVIES — I can only identify the deficiency, given that we are a complaints-based organisation. It would be for others to come up with a funding model that would support better access in both inpatient and community-based palliative care.

The CHAIR — I will follow on from Ms Patten's specific question about legislative change. I know it is not your bailiwick, so to speak, but we have heard some interesting evidence preceding you — as Ms Patten said — from the law institute. Communication is obviously an issue, as you are saying. The law institute in their submission said the legislative framework currently is not clear and not centralised, which creates uncertainty. Is there anything you would like to say in response to that?

Dr DAVIES — I think having different pieces of legislation dealing with different aspects of people's wishes when they are not able to make decisions for themselves is problematic. I think there are ways around that. For example, making sure that each piece of legislation is consistent in terms of the hierarchy of who can make decisions for people in the absence of an instrument to do so. But I think as far as possible there ought to be a single point of reference for people who are faced with not being able to make decisions for themselves some time down the track.

The CHAIR — Is there anything further that you would like to say to us before we conclude?

Dr DAVIES — No, thank you. I appreciate the opportunity.

The CHAIR — Thank you very much.

Witness withdrew.