TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Shepparton — 13 August 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

<u>Staff</u>

Secretary: Ms Lilian Topic

Research assistants: Ms Annemarie Burt and Ms Kim Martinow

Witness

Ms Annette Cudmore, Clinical Nurse Consultant, West Hume Palliative Care Consultancy Service.

The CHAIR — Welcome to the committee, and thank you very much for appearing before us today. 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's 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 of the transcript within the next week. The transcript will ultimately be made public and posted on the committee's website. We have allowed half an hour for our session this morning. You are the clinical nurse consultant in the palliative care part of the Goulburn Valley Health?

Ms CUDMORE — I might clarify that. I am the West Hume clinical nurse consultant for palliative care. I have been in that role for the last $2\frac{1}{2}$ years. Initially when the department was looking at expanding their consultancy service for palliative care, the funding went to our community palliative care service, so I sat in that role over there for $2\frac{1}{2}$ years, and have been in my role as the West Hume clinical nurse consultant, but stepped over into Goulburn Valley Health to support the development of inpatient palliative care. I have been in this role for only four weeks.

Regarding the scope of what I can discuss today, I have a quite extensive background in community palliative care within Shepparton and also across the West Hume region, which is the Shire of Moira and down to the shire of lower Hume, which goes out to Yea, Alexandra, Seymour, Kilmore and that area.

The CHAIR — We look forward to hearing about your expertise across that broad area.

Ms CUDMORE — I will start the session by saying that Shepparton has been very fortunate in having an extensive, well-developed community palliative care service. Historically we have done palliative care and end-of-life care in the community very well. When I look across to our other regions that I support, down into Moira and lower Hume, and if I go back $2\frac{1}{2}$ years, they were really struggling with their provision of community palliative care. That was really based around a couple of factors; it was around resourcing, knowledge and capacity. My role in that consultancy role has supported and developed our very small palliative care services that cover a very big area to improve their scope and their capacity to allow people choice, especially to die at home.

I was speaking to my Moira palliative care nurses this morning. Two years ago their specialist palliative care nurse said to me, 'Annette, none of our patients want to die at home. They will just die in the small hospitals because they see that as their home'. They are now having probably a death a week at home, which is fantastic. So it is around how we translate care between acute care and community care. I have been in my role at Goulburn Valley Health for only four weeks. In my other roles we had very good in-reach services into Goulburn Valley Health and I have had extensive exposure to Goulburn Valley Health's processes around palliative care and end-of-life care.

I was reading about this. One of the big things for me is that we still have not got the community awareness and the recognition and understanding of palliative care versus end-of-life care. People think that palliative care is about dying. If we are going to achieve anything out of this, we have really got to achieve a much greater community awareness around what palliative care can offer and what it stands for. I say that because I was looking at your website, and I was amazed to see how many submissions were around euthanasia. I think we have not really got the community awareness out there around what palliative care can achieve and how we can do it. In my role at Goulburn Valley Health that is probably one of the biggest barriers to doing end-of-life care and palliative care well, because the message to the medical team is still not there that palliative care is not just about dying. It is about quality of life, it is about how we live with our illness, it is about choices, and it is about where we want our care, who we want to be involved in our care and how we bring all that together.

My role with Goulburn Valley Health is to work on that as a priority and to try to get the system improved. I was listening to Carolyn as the after-hours manager talk about the translation from the emergency department through to organisations. Goulburn Valley Health has made a commitment to palliative care and we are hoping to develop an inpatient consultancy service. At the moment there is me and some other assistance, with some of our other physicians supporting that, but until we get the specialist expertise so that can walk people through emergency and wherever else they go, I think we will struggle with having different teams involved and things like that. People should be able to come in under a palliative care bed card right from the emergency department and therefore then get the continuity and the language that Carolyn was alluding to and the continuity and care approach that Carolyn was alluding to.

My role with Goulburn Valley Health has, even in four weeks, really supported and assisted that. I go across all specialties. I have been in the emergency department numerous times, in intensive care and in paediatrics. I think one of the other things that we have really got to be clear on is that death and dying happens everywhere, and we need to ensure that our skill set amongst our staff — whether that be our doctors, our nurses or people who are providing meals — realise that they will come across it no matter where they work. We need to be mindful that we do not create a specialty of palliative care. Rather we need to skill people across all dimensions in being able to care for someone who is dying, which is incredibly important.

I struggle with advance care planning because it has somehow sat within palliative care and end-of-life care for a while and it needs to sit out of there. It needs to sit in subacute care and in general practice. We need to be having the conversation so much sooner than when we are sitting in the emergency department with our loved ones who have had some catastrophic event that may push them into end-of-life care. If we are really serious about advance care planning, we need to resource it properly. Goulburn Valley Health has made a good attempt at advance care planning, but it kind of falls into a whole lot of subsets and there are people picking up on top of their roles. We need to have people, as Carolyn was alluding to, with the language and be able to have those really sensitive conversations with people at the appropriate times. Until we actually resource it a little bit better, we will probably struggle with that being done. Until we get the community awareness and people having the conversations out in the community much earlier, we will struggle to have that living document travel with people along their care pathways.

In amongst advance care planning comes our legislation. I know that we deal with people from different states because we service patients from Tocumwal, and patients from other states come here. Most of the advance care planning and the legal processes are different state by state, which can cause people to have some concerns and also create some confusion. I think we need to articulate advance care directives and what they mean within the legislation in the health system. If we are putting the importance on advance care directives and advance care planning then we need to take them seriously and we need to look at them and utilise them to guide people's care a lot more than we probably do now. I am speaking of this in regard to the acute health system rather than to the community system. As I said, I work very interactively with the community team and we actually do quite a bit of advance care planning in the community, and yet when they come into hospital, especially regarding the not-for-resuscitation process, that has to be redone on every re-admission. There are some things that we can tidy up and things that we can do better in regard to that.

I suppose the other thing, — and this sits within advance care planning and also within palliative care and end-of-life care — is the community awareness around the expectation of how we have medicalised health. People kind of expect that we can fix everything. That is because we have done so much with research and we have done so much with advancing care treatments. I was having a classic conversation with a chap yesterday, who is very focused, even though he has got widespread disease, on having some more radiotherapy, because it might help; and it has helped in the past, even though he cannot even get out of bed and his ECOG status is very low. So, from a health perspective, what role do we have to play within the decision-making process? Should we be offering things that we may know are not going to give the person a lot of gain. That is tricky; that takes a lot of conversation and a lot of discussion to be able to help with decision-making processes.

I just want to pick up on the cultural thing because I did not know if Carolyn had articulated that quite well. You are right, Shepparton is very multicultural. One of the challenges for us has been a lot about Aboriginal communities sometimes not liking coming to hospital, and so do some of the other cultures. They struggle with being in an acute care facility because of the language and because of how we approach them. We have done lot of work in our community with community healthcare in engaging people in the cultural groups that we serve. Our community palliative care team actually look after our cultural patients extremely well at end of life because they have developed relationships over the many years, and so there is that trust. We do it their way, not our way. I think in an acute care system it is very hard to let go of our way and do it their way. So I think they are probably the main things that I want to articulate and I know that you have the community palliative care team later, which is really good.

The CHAIR — Thank you very much, Ms Cudmore, for a really insightful presentation. I wonder if we might pause now and ask Dr Bhattacharya to join us at the table so that we can ask questions of you both.

Witness withdrew.