

# 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

#### Witnesses

Ms Cheryl Bush, Executive Manager, Clinical and Nursing Services, and

Ms Nicola Gorwell, Palliative Care Nurse Practitioner Candidate, Gippsland Lakes Community Health.

**The CHAIR** — I would now like to welcome from Gippsland Lakes Community Health, Ms Nicola Gorwell, a palliative care nurse practitioner candidate, and Ms Cheryl Bush, the executive manager, clinical and nursing services. Thank you very much for being here with us this afternoon.

Before we start, I will just 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 and 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.

Again, the committee really appreciates you travelling to meet us here today in Traralgon. We have allocated half an hour for our session, so I would invite you to make some opening comments and thereafter the committee will have questions.

**Ms BUSH** — Thank you for the opportunity to speak here today. We will be really talking about our insights and experience pertaining to palliative care and advance care planning, with the particular emphasis on or from the perspective of East Gippsland and the uniqueness that we face in our area. I think we would really like to focus on the area of community engagement and the roles that can facilitate that being effective.

To start with, as it may have been mentioned in other sessions, the terminology and language that we use and perceptions around palliative care greatly influence our ability to effectively implement palliative care. There are different perspectives, and the negatives when euthanasia and other things come up are probably more in relation to a lack of understanding about what palliative care is and when it should be implemented. The effects of poor palliative care I guess would influence it too.

We clearly believe that good palliative care would negate the need to consider euthanasia. Nicola can probably share some experiences she has had where we have had people who have identified that they wanted to end it now but that with explaining what is going on, what to expect and what we can offer from a palliative care perspective, those people have actually chosen the completely opposite path. So I think getting that understanding at community level is really important.

We have had some projects that we have been involved with through various funding that we have received. One was pertaining to engaging the community in advance care planning. We gave the project the name of 'Making the Last Chapter Reflect the Whole Book'. In this project we engaged community members who were volunteers with a bit of training and presenting the concept that if we can understand about people's life up until that point, that is the book; and how can we make the last chapter reflect that from their values, their beliefs and what is important to them. That project was funded through the Department of Health via Palliative Care Victoria. It has just completed, and we are continuing on with that as we go. The feedback we have had is that people really want to talk about this stuff but they do not have the venue or the opportunity to do that. What this project has done is create a safe environment or an opportunity for that conversation to happen.

The volunteers, along with a Gippsland Lakes Community Health staff member who has been involved in the project, have been delivering this to community groups. The volunteers themselves identified their connection within the community, and we have delivered to those groups. We have delivered to staff. Our home and community care staff were particularly keen to do it. We have delivered it to our staff within the organisation as well. What it does is create that opportunity: 'I attended this training or this session, and this is what we talked about'. So then they have a conversation with someone else and it kind of just spreads out through the community.

The original proposal for this project was that we would hand it over to a community organisation. To this point I guess there is a level of sensitivity in dealing with discussions around death and dying, and we are nowhere near that phase at the moment. We did put out expressions of interest to community groups, but I guess it is a reflection of the community and the willingness to feel comfortable talking about those areas.

The other project that we had was working with our Aboriginal community, and I might hand over to Nicola to talk about that one.

**Ms GORWELL** — That was the project that I undertook this year and completed just a month ago. That will be an ongoing commitment to what we have developed. Initially it was a consultative process with the Aboriginal HOs that we have in our region. Initially we were going to work with Lakes Entrance, LEAHA, but I had actually built up a rapport with one of the Aboriginal liaison officers at Bairnsdale hospital. After some consultative processes, she was the one who ended up picking up on the project and she thought that it would be a really good thing to implement. We decided on using the genogram as a way of introducing palliative care to community members who have a life-limiting illness. We found that it was a really simple and safe way of just getting to know the actual client. Pivotal to that was working with an Aboriginal health worker. They were there with us. They actually knew the client. They had actually built up trust and rapport.

From that we were able to gather so much information. The Aboriginal health worker I was working with the first time said, 'That was actually incredible.' This person initially did not want to talk about it. The family did not want to talk about it, either. But just by presenting it as a way to get to know you, we talked about where you had come from and from that who the family members were, we worked our way through. So in the end we were able to discuss 'Who do you think would be the best person to be your medical power of eternity? Who would be the best person to have financial power of attorney?'. We worked out where home was, so where country was. Some people had come from the Murray and then moved to places like Orbost and had family there. They said, 'Although family want me to go back to the Murray, this is where my home is. It's where my children grew up'. So we were able to ascertain that very early — and that was an early referral, too. That is another thing that we are really trying to push, too, early referral to a palliative care service.

Initially we had someone that would not talk about it and family would not talk about it. At the end of the conversation she was able to tell us what she was going to wear in her coffin and what the coffin was going to look like. It was just a very simple tool but we were able to gather, again by having the Aboriginal health worker and allowing them to tell their story. Families are so extended, that was the other thing. We were able to talk about especially financial power of attorney — I think that is very important — and medical power of attorney, especially in big extended families. They realised that they would have someone there who would be able to manage their finances, because another big problem in the Aboriginal community is elder abuse. They said if there was someone that everyone agreed was going to manage that, they agreed.

The other thing that people worried about often was what would happen to possessions once people died. That is another thing. Often there is ongoing family disharmony. So it was decided early, who was going to have what. It was that sort of process, and it was very simple.

From that the family — the two daughters and the elder — were able to go home and say, 'We're going to have a family discussion'. They also named who was going to be a part of that discussion so that everyone was on board. There were actually foster children that she had had that she said were a very important part, so she wanted to make sure that they were involved as well. It was just a simple way of being able to gather so much information. From that then there was an advance care plan that they were going to be working on too.

I spoke to the Aboriginal health worker and said I was coming today. I said, 'What would you like me to say?' and she said that. She also said, 'The other is very clear communication and also making sure that an Aboriginal health worker is involved in any of that sort of process, because they know family, they know community and they know where people have come from'. Again, it is getting back down to the individual. She said, 'We talk about being culturally appropriate, but we're all individuals. For some of us we still have very strong cultural beliefs but for others we are more mainstream, so for others it's very different'. Again, it is getting to that individual. I think that is why the genogram can really specify that, because from that we were able to talk about, 'As an Aboriginal person, what would be important to you at end of life?'. I think that was the other thing, that it cannot be the same for all because they are Aboriginal.

**Ms BUSH** — That probably leads into the next bit that we wanted to present and that was about from a community perspective what are the key roles that we see that we need to continue to support. Certainly that role of the Aboriginal health worker being part of the palliative care team is really important. To get a relationship with an Aboriginal person per se we found that that takes time. It is not just that you meet someone and it is going to work. So some of the success we have had with that project is because Nicola has built a working relationship with the Aboriginal health workers.

With the Aboriginal health workers, there was also another element to that in that the ones who were part of the project tended to be more towards the elders within the community as well. We had some young Aboriginal

health workers and they were the ones we did not get off the ground with. We respectfully think that it may be that because their standing in the community made it really uncomfortable for them. They were really engaged in the concept and the idea and fully supported that, but I think they were not in the right position within the community to actually fulfil that role. So when we reflected back, that was what we saw. The health workers that were older certainly embraced it and felt more confident with it going forward.

**Ms GORWELL** — Yes, and I think the community respected them more too, because it is not the younger person then going to an elder to be talking about death and dying, but from an older person and an elder — we had an elder as well — they are highly respected, so that is something that they can appropriately speak about.

The other thing that came out of this is about the male-female as well; so it would not be appropriate, unless I was with a male Aboriginal health worker, to speak to another male. So again, it was female-to-female Aboriginal health worker with a female, and the male as well. That is another issue as well. Again, it is about being an elder as well and being older — it is gets that respect — and a lot of our Aboriginal health workers were younger, so they did not feel that they were in an appropriate position to be able to talk about things like that.

**Ms BUSH** — The other role that we have seen significant improvement in in the delivery of palliative care in East Gippsland has actually been Nicola's role, so the nurse practitioner candidate role. It has been pivotal in engagement with services. I am not sure whether you are familiar with the landscape of East Gippsland, but we have got bush nurses, so sole practitioners in remote areas — the small rural health services — and Nicola's role has been covering the whole of East Gippsland. In recent times we have had quite a few bush nurses who are managing people who are wanting to die at home, and Nicola's role is not only being the specialist input from the palliative perspective but also the support that those bush nurses need. They do not deal with palliative care day in, day out, throughout the year, so when they do come across a client, then having someone who is actually going to come up and stand beside them to work through with them, to support them — there are no GPs out there — it is a really important role.

The feedback that I get from those staff remotely, and small rural health services, is really appreciative of the role. I can see that, particularly with East Gippsland's population being an elderly population, Nicola's role would actually see the growth of another person to take on that role as well, because it has been so pivotal. There has been significant work that Nicola has done in working with GPs. We are dealing with — in East Gippsland, the GPs have been doing palliative care, seeing it as a core part of their work for a long time, and to introduce a new role does not happen easily. It is really walking a fine line to be respectful. The key things that Nicola has done to make it work are really sound communication and working at keeping the GP at the centre, because they are the ones who have often known the clients for the last 20 or 30 years and have almost an ownership over it. It is really about a relationship that they have actually built with the client, and if other people are coming in and not working with the GP, then the whole thing tends to fall over.

I think the other part around that is that palliative care as a specialty is relatively new. We have forever had cardiologists and forever had nephrologists, but the specialty of palliative care is very small and very new in relation to those time lines. When we have had people trying their best to manage people who are dying, and controlling their symptoms, to suddenly have a new specialty that is moving in on their territory can be a little bit threatening, but I think we are progressing well in that field and actually seeing that that negative publicity that sometimes comes out and where euthanasia raises its head, is less likely if you have actually got the input of specialty services.

We have had some really young and complex cases in recent times, and the GPs have really come on board with that specialty service happening. And that it is happening locally is the other point that I probably want to make. We have had specialists actually come in to East Gippsland as far as Orbost. Did they get to Omeo?

**Ms GORWELL** — No, they have not, just to Orbost.

**Ms BUSH** — But I think it is just that appreciation of the fact that it is very easy to be in Melbourne, or even here, and not appreciate that while Mallacoota might be only so many kilometres on the map, to drive there is exhausting, so for clients to actually be accessing services back down this way, it is a big ask. A lot of them choose not to, and that is not fair, and it is not what we want to see as far as palliative care. Everybody should have access to palliative care.

**Ms GORWELL** — I think especially, often people living rurally and remotely will say, ‘I was born on this farm, and I want to die on this farm’. So it is about a sense of place and a sense of community too. Again, if you are not well and are having to travel to Melbourne or to other places, it is really not conducive to really good care.

The other thing we were talking about is that when we talk about telehealth and things like that, which is still with the NBN, is another issue for us. Hopefully in time that will be another thing that will improve, but at this point in time it is very unreliable. It does take a lot of time to set up. Often there are multidisciplinary meetings, and we have got 15 minutes with a specialist from Melbourne, and then when your technology does not work, it makes it very difficult.

**The CHAIR** — Fantastic. Thank you. I might ask the first question. I want to learn more about those two projects you talked about. The Indigenous project obviously sounds like it is working really well. With the other project you mentioned, Cheryl, are you doing advance care planning with people you are having these conversations with?

**Ms BUSH** — Yes, it is the introduction to advance care planning, so it is really about people reflecting and thinking, ‘To make that last chapter in my life reflect my values and beliefs of the first however many chapters of my life, how am I going to do this?’. The session that we deliver actually gets people to that point. It gives them some pointers. We have got an advance care planning nurse under community health for one day a week, or they can go to their GP, but we give them the options around that — taking that next step.

So it is really the primer for people to even start thinking about advance care planning, because most people do not think about it until they are in a crisis situation in the hospital where decisions have to be made, and we have lost that opportunity to do it in a less stressful environment where people have actually had time to think things through and they are not expected to make decisions bang, bang, bang. That is what we are really achieving. It is probably not a threatening way of going about it.

We have been looking for ways that we can engage with the consumer that are not threatening. People hear the words ‘palliative care’, and they do not want to know about it. If we can come in underneath, at the ground level and influence from that perspective. That is why we use volunteers. They are community members, and they have got connections within the community, so it is not trying to enforce something on them. They were part of the development of the actual sessions we end up delivering.

**Ms SPRINGLE** — Thank you very much. It was really interesting hearing about your work. Earlier you said you feel like the issue of euthanasia comes up when people are not aware of what is open to them in terms of palliative care. On the flip side of that we have heard testimony today, and at other times, around the idea that perhaps there are not appropriate responses to acute and severe ongoing pain.

**Ms SPRINGLE** — I would like to hear your reflections on that, because obviously there are a whole lot of different aspects to that issue in itself.

**Ms GORWELL** — I have actually got an example of that just this week. We had an inpatient who actually had said, ‘Look, if someone can get me a gun. If I was out, that is what I would be doing’. It was because the pain was totally uncontrolled. Once we were able to engage with a specialist service — that was the phone call I had got, which was, ‘We have an inpatient, and he is talking — this is what he has expressed’. It was going in, and it was about symptom management. That is what it was all about, uncontrolled pain. I was able to engage with a specialist service in Melbourne, get in a pain regime and we were able to manage things. They said they just could not believe it. They said, ‘If I knew that this was going to continue — where this is going is cruel, absolutely cruel’.

As you said, it is about symptom control. I think in all of the experiences I have had, that is what it involves. That is why it is so important to be able to get early referral too, so that we can start with good symptom management. A lot of the time it is where it has been a late referral and things have not been managed well. It all ties in together. It is the psychosocial issue. We know that we look at the whole person, so when there have been other things going on, things have not been managed, there have been psychosocial issues, they have a lot of existential distress and things all adding to it.

If we can get an early referral, so we can get in supports, we can get to know family, we can build trust and rapport, get district nursing or community nursing services going in on a regular basis, then having access to a specialist service as well when needed, so then there is good symptom control, I find that those sorts of issues then are abated.

**Ms BUSH** — I just add to that that I think in palliative care in symptom management as the specialty has come to age, pharmacological management of those symptoms has advanced. Where the traditional morphine — —

**Ms GORWELL** — Midazolam.

**Ms BUSH** — Midazolam was the mainstay management. There is a lot more knowledge about the effects of those medications and other medications that can give better relief as well. That is the change that we have even observed in the last 18 months or so.

**Ms GORWELL** — In having the specialty services we do have access then to all of the adjuvants that we can use now. We now also have access to fantastic imaging and things like that, but then having someone who can look at that and actually understand what is going on, so having that specialist service available in rural and remote areas, can make such a difference.

**Ms SPRINGLE** — That being so, do you think you can foresee cases where even early intervention would not necessarily be enough?

**Ms GORWELL** — Early intervention? Yes, as we have spoken about, there are cases where in my experience there was no indication that they were going to end their life, but they did. A lot of the ones that I have been involved with who actually indicated that is what they would do is because of really poorly managed symptoms. It is also about choice as well for a lot of people. You know, if there is not the support network, what is going to happen to them? I think that fear factor is another thing. If we can get in early as a palliative service — and our support people — our chances are greater than if not.

**Mr MELHEM** — Thank you both. From a priority point of view for the Victorian government, for example, do you see the priority should be given to giving access to improved palliative care versus changing the current laws, which may include voluntary euthanasia? What are your comments on that, and why, I should say?

**Ms BUSH** — I strongly believe that in palliative care we have still got a lot of room to improve. Palliative care is not just about medical care. It is about the whole person care, as Nicola said. If we can improve support — and one aspect that we have not mentioned is the carer. If we can hold that client and their carer and be involved in supporting both early, and doing the genogram that Nicola talked about — it is not just for Aboriginal people; it is for everybody. That simple tool allows a conversation to happen, and we pick up very early from using that tool about the psychosocial circumstances, so we can put plans in place or put supports in at appropriate times that we know about. If we do not know about it, then we are not doing anything about it. That is where the spiral goes downhill fairly quickly.

**Ms GORWELL** — I think often when you do speak to people about it, they have actually had experience of someone else's death that was difficult. Often people will project, 'Well, I don't want to die like' — someone else died — 'because that was just horrific, and I am frightened that the same thing will happen to me'. I think, especially in some of these smaller communities, bereavement is another big part of palliative care that we really need to be able to improve on — access to bereavement. Especially in communities if there has been a lot of protracted bereavement, people pick up on that. 'If that is what is going to happen to me and that is what I am going to drag my family through — I do not want to see my family have to go through all of that that they went through'. That is another aspect of it.

In time if we had better access and earlier access, I think that is one way of improving people's outcomes and their perceptions. We sensationalise the bad deaths, but we do not talk about the good deaths much. You do not see any of that. We do not talk about the good deaths where people were well managed and families were supported.

**Mr MELHEM** — Do you then have triggers to encourage people to have advance care plans, for example?

**Ms GORWELL** — Yes, we do.

**Mr MELHEM** — And what would be the triggers?

**Ms GORWELL** — On admission. So that is something within the district palliative service. Advance care planning is in the admission. That is one thing that we do. We make sure that people have an opportunity to do an advance care plan.

**Ms BUSH** — Again that genogram is really a platform to explore all sorts of things, and it comes into that conversation at that point.

**Ms GORWELL** — Yes, when we do the genogram.

**Mrs PEULICH** — Can you tell us all a bit about the genogram? I ask the obvious and the simplest question.

**Ms BUSH** — In its simplest form it is a family tree.

**Ms GORWELL** — We call it a family tree or family mapping, and in the group I am working with at the moment I have two Aboriginal health workers plus an elder. At the moment we are formulating one, as the genogram that we have is quite clinical. It is the one that they use at the hospital, and it is used for social work and allied health. We have decided we are going to make our own, one that will be identifiable for the Aboriginal people in East Gippsland. They have said we need a bigger form as well, because they have got big extended families.

The way we introduce it is we just say, ‘This is a way of getting to know you. Now that you have come into our service we would really like to get to know you. If you are happy’ — and most people are happy — ‘we just want you to tell us your story’. It is from the very beginning, and we encourage them to do it as well. We are not prescriptive. In the social work model they are very particular, but we just say, ‘If you can just put who you are’. We name it, and we just go through, ‘Where were you born? Who were your parents? Tell us a bit about that’. Often then they will talk about maybe siblings or people who might have died. We can pick up on a lot of losses that way as well. We work through, ‘You got married; who were you married to? Who are your children?’. It is just a way of working through. Then we start to talk about their interests. Especially for Aboriginal people we talk about where they came from and where they consider country. We just quietly say, ‘Did you attend church? Were there any particular religious traditions that you had growing up about your children, family, friends?’.

It is just a way of unpacking that. Then we talk through that and we talk then about the advance care planning and having a financial and medical power of attorney. Then we can look at the family and say, ‘Who do you think in this family would be an appropriate person to take on that role? Who would you feel would be able to manage that?’. Then they usually can say, ‘Look, my daughter is the one that is the most — I think I would’. Then they can see too it is a path, that they are part of a family and a community. Conversely too we often find when people feel like they are isolated. They can actually see that on that bit of paper that they are isolated, and that is when we can talk about resources.

We did introduce it as part of another project I did, and it was within the whole community but non-Aboriginal members. We introduced it in some of the remote areas where the remote area nurses find it difficult for people living on isolated farms. They say, ‘I’m going to be fine. I’m going to stay here and I’m going to die, and this is where I’m going to be’. When we actually do the genogram they realise they are quite isolated, and we say, ‘When you get to a stage that you are not able to look after yourself, who will be available to do that?’. It is just a visual. I think as a visual people are able to see that and make up their own minds about things. It is a way of listening and that sort of conversation, and it is non-threatening. Rather than someone just there with a bit of paper asking questions, it is about them engaging. And it is their story, so we try to present it that way. It is about their life.

**Ms BUSH** — We have also had pets, because that becomes an issue.

**Ms GORWELL** — That is most important — animals — and often people will not leave because they have got animals. We have done that too. Where they are very close to the animals, we decide who is going to have the pet and the pet starts having some stayovers. They are then quite comfortable that when they die their animal is going to be looked after, and I think that is a really big part of good care. The other thing about having the genogram — and we also write all over it, what are their wishes, and we then put on the back — is they can

present that to families, especially when you have got families who are not agreeing. They can say, 'Look, these are my wishes, this is my life, this is what I want'. Again, it is another visual where families can see that this is their loved one's life. Rather than a piece of paper — —

**Ms BUSH** — Pages and pages of writing that no-one can read.

**Ms GORWELL** — And people scribble on them, put pictures on them and whatever. It makes it very individual. Again, when we were talking about the Aboriginal community, they are individuals. We are all different. Some people, as I said, would like to have a Christian service and hymns, and for others it is about the smoking ceremony and going back to country. Again, we need to be able to ascertain that early in the piece so that we can put in plans for that to happen, rather than when they are in their terminal stages and we cannot transport people.

**The CHAIR** — I would like to thank both Ms Gorwell and Ms Bush. Thank you both very much for coming down to Traralgon as well. We really appreciate it. I think you have given us a perspective we have not heard from all our travels across Victoria thus far, so we really appreciate what you had to say and the feedback you have given us.

**Witnesses withdrew.**