

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Traralgon — 9 September 2015

#### Members

Mr Edward O'Donohue — Chair

Ms Nina Springle — Deputy Chair

Ms Margaret Fitzherbert

Mr Cesar Melhem

Mr Daniel Mulino

Ms Fiona Patten

Mrs Inga Peulich

Ms Jaclyn Symes

#### Participating Members

Mr Gordon Rich-Phillips

#### Staff

Secretary: Ms Lilian Topic

#### Witnesses

Mr Luke Williams, Clinical Lead,

Ms Naomi Griffiths, Assistant Manager, Ambulatory Care, and

Ms Jenny Turra, Palliative Care Nurse Practitioner, Latrobe Community Health Service, Morwell.

**The CHAIR** — I declare open again the Legislative Council legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. I would like to welcome the Latrobe Community Health Service and in particular Ms Naomi Griffiths, Ms Jenny Turra and Mr Luke Williams. Thank you very much for joining us today. Before I invite you to make some opening remarks, 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. You will be provided with proof versions of the transcript within the next week, and transcripts will ultimately be made public on the committee's website. We have allowed 45 minutes for our session today. I invite you to make some opening remarks, and thereafter the committee will have questions. Thanks again for joining us.

**Ms GRIFFITHS** — We are from Latrobe Community Health Service; we are from the palliative care and district nursing service. We are called ambulatory care, so we do both palliative care and district nursing. Our nurses go to see palliative care clients in their homes. We provide support to both the families and the client who has the palliative care diagnosis. I might pass to Jenny, because I am in the office more than I am on the road with these girls.

**Ms TURRA** — I am Jenny Turra. I work as the nurse practitioner in palliative care in the Latrobe region. I was endorsed in January this year. Much of my role is working with clients and their families, particularly around symptom management and support, as well as working with GPs and providing mentorship, guidance and assistance as it is needed. I work closely with a specialist palliative care team. We are supported by Calvary Health Care from Melbourne. We have a really close relationship with that team.

The majority of our work is within the community setting. I do, on occasion, when I am asked by Latrobe Regional Hospital, go into the hospital and provide some assistance where necessary. We also attend discharge planning meetings as well as the weekly palliative care meeting at LRH to try to help the transition from hospital to home or also assist with relationships, getting clients into hospital if that is needed as well.

I guess from a palliative care perspective, I started with the service probably five years ago. Within that time we have grown from probably 30 palliative care clients at that stage to nearly 100 currently, and our funding has not changed within that time. That creates a lot of challenges for our service, and I guess we are currently looking at our model of care to see how we can do it better, and with the increasing need of the clients and carers within the community, with the same funding.

**Mr WILLIAMS** — G'day. I am Luke. I am the palliative care and complex care clinical lead from Latrobe Community Health Service. I guess it all rolls into palliative care at the moment. I am only new to the role and new to the area. I have previously worked in palliative care at Melbourne, and it is a very different environment. I am seeing disparities between the access that people have to support out here and what they get in Melbourne. That is one thing that I can really identify as a big gap there.

I think this is a great initiative, and I think it is something worthwhile looking into. I think the choices for end of life are not always there. A lot of people — and the majority of people — express that they want to spend their end of life at home, and it is not always a possibility, just because of resources. I think as well as that it is a great initiative because we do not talk about this as a society — death is often ignored. Going into someone's house, as I do a lot, and talking about death and what they want for end of life, they are often thankful for having that opportunity, because we ignore it as a society. We get to a point where push comes to shove and our wishes are not adequately expressed, so we are leaving our loved ones to make decisions when we do not really know what this person would want. So I think it is a great initiative, and I thank you for the opportunity to be involved in it.

**The CHAIR** — Thank you very much for those opening remarks. I might start by asking a couple of questions. First of all, Luke, if you could expand on the differences you have seen between metro Melbourne and here in Gippsland, because we have heard of differences in the western part of Victoria and northern Victoria, and we are keen to hear about Gippsland. Jenny, I would be interested to know how you have managed to make 30 into 100 over that time. Perhaps I could put those two questions first.

**Mr WILLIAMS** — I worked for a specialist palliative care team in the community, and the resources that we had in terms of nurses was well above what we have here at LCHS. We had a doctor on staff; we had a nurse practitioner on staff. Jenny is a fantastic resource. There needs to be more of these hardworking people, especially in environments like this. In Melbourne you have got five major hospitals within 30, 40 or 50 minutes, but we do not have that out here. We do not have these specialist palliative care physicians to just call on, and we do not have the respite beds. We do not have the specialist palliative care beds available that you do in Melbourne. The options just are not there.

As well as that, options for in-home respite — they are just not there. We had a carer respite worker who was employed by our organisation in Melbourne to do respite, whereas respite here is basically limited to the commonwealth respite service, and that is, I understand, in high demand as well. That little resource just does not go too far. Those are the sorts of things that we need to keep people at home — to die while at home.

**Ms TURRA** — I guess what the literature tells us is that palliative care, if we can get in early and build relationships with people — if they are referred in a timely manner — then we can get supports in place. We can have those discussions about what it is that people are wanting, what their values are — discussions around end of life — when they are reasonably well. That is something that as a service we have really focused on and spent a lot of time promoting within the hospital, with GPs, doing education sessions, providing guidelines for when is an appropriate time to refer to palliative care, and as a result our numbers have grown significantly and we have increased the palliative care stable population on our books as well.

But at the same time, whilst I think that is the expectation of the community, as well as within the literature that is what we are being encouraged to do, there are not the resources or the support to actually provide that service. I know from our perspective we struggle with the resources that we have as well as struggling often to see these people, depending on what their needs are and how often they need to be seen. We need to compromise sometimes about whose needs are higher, and that has implications for relationship building, for people's trust, and I guess people sometimes get quite disappointed in the service because we cannot be there when they need us to be there.

I think the expectation in the community, and perhaps how they see our service, is that we should be able to provide perhaps a 24-hour service. Whilst we are on call, we are not there to be the people or person to be assisting with 24-hour care. Generally those people who do need respite or assistance are entitled to 2 or 3 hours a week, and they are caring for somebody 24 hours a day, 7 days a week, so that really does nothing to support that carer.

We had a carer yesterday who is desperate for carer respite for her two family members. Her experience has been, whilst she has been in contact with different services and has gone through the system of getting her mum and dad to be able to access respite because they need ongoing assessment along the way, that has become very frustrating, and she no longer wants to engage with any services. So now we have a carer at home who is totally exhausted, overwhelmed, very angry with the health system and very disillusioned with the care and support that can be provided. Whilst we are saying one thing, the reality is quite different.

**Ms PATTEN** — I just wondered if you had given any thought as to what sort of recommendations you would like to see us make at the end of this, apart from, obviously, more money.

**Ms TURRA** — Yes. I think from my perspective, I attend a meeting in Melbourne of different services, and we talk about what is happening Victoria wide. There are some great initiatives that are happening. Metropolitan seems to be way ahead and have the supports and the services in place, whereas, for example, we do not even have a social worker who works with our team. We have a grief counsellor who works sporadically when there is a real need, whereas I think metropolitan has access to all these wonderful services and support, and generally it is the nursing staff from our health organisation who do everything.

We are not qualified social workers; we are not qualified counsellors. We are doing the best we can, but I think we can do a lot better for our clients and carers regionally. It seems to be a real disparity, from what I see and from what I hear from colleagues.

The nurse practitioner candidacy program was developed as a gap was identified in palliative care provision, particularly regionally and rurally. I was a candidate for a period of four years, and I feel like I do make a big contribution — that I am able to make a difference and improve people's quality of life. But what I am hearing

is that there might not be funding to continue with the nurse practitioner model, so I guess that is quite disappointing when we know there is a cap there and we can make improvements. But it seems to be very much guided by what funding is available, not necessarily client outcomes.

**Mr WILLIAMS** — I think another real area that we could improve on is education. As Jenny said, often we, the nurses, are going out and playing the roles of the counsellor and the social worker and all these different roles. We cannot always do that, because we do not have the expertise, but there are lots of great educational resources out there from people like Respecting Patient Choices. If we had access to that education across our staff, I think things like that would give us and our staff the confidence to be able to do that more effectively and improve the outcomes.

**Ms TURRA** — And the education tends to be available within the city. It does not seem to come to the country, which creates challenges I guess for workforce as far as allowing study leave. It is very challenging.

**Ms PATTEN** — Yes. If the education could come to you, rather than you going to it.

**Ms TURRA** — Yes.

**Mr WILLIAMS** — Absolutely.

**Ms PATTEN** — And greater allied health out here.

**Ms TURRA** — We are fortunate in that we have access to physio, dietetics, speech et cetera, but, yes, as far as the psychosocial goes, it is very much lacking, and that is such a big area. Much of my work is psychosocial, and I think we could do a lot better with the expertise that is available. We just currently do not have it within our service.

**Mr WILLIAMS** — And carers miss out on so much. I think a real focus needs to be on the carer and championing support for them — support networks, even just having groups to facilitate discussions with people who are in a similar situation — not just whilst they are going through it but after the fact as well. They are the hardest working people. I go out for 8 hours a day, and I go home exhausted, but they work 24/7. I think that they do miss out on a lot, and sometimes they just get forgotten.

**Ms PATTEN** — I think you are right.

**Ms SPRINGLE** — We have heard a lot about resourcing and the lack of resourcing and what have you, but in terms of recommendations — if we can try to focus away from funding and resourcing and what have you — are there mechanisms or frameworks that are limiting you? Are there better ways that you could be enabled to do your work, I suppose, in terms of end-of-life choices and servicing patients' needs and wants in that regard?

**Ms TURRA** — I think one of the difficulties that I particularly have is — I have spoken about what the research is and what we are encouraged to do — when to admit someone to palliative care. Maybe that is something that we need to look at so there is some clarity about when the right time is. Given that it is unlikely that resources are going to increase, but our clientele is increasing, perhaps that is something that needs to be looked at, as well as what is end-of-life care.

**Ms SPRINGLE** — Do you mean admission into palliative care, when is the right time for that?

**Ms TURRA** — Yes. I guess from my perspective and my research and evidence, it is admit early, but the reality is our numbers are increasing and we do not have the resources. So perhaps we need to relook at when is — —

**Ms SPRINGLE** — Would you say that there are people who are not going into palliative care because there is no space for them?

**Ms TURRA** — We are currently very fortunate — and maybe you want to speak to that, Naomi — around our HACC service because we are palliative care as well as a HACC service. I might let Naomi speak to that.

**Ms GRIFFITHS** — I guess we are fortunate in the way that if we do not have the resources available to admit as a palliative care client, we can at least get some HACC services in, so we can start supporting the

carers by helping out with medication and administration or hygiene assistance or some of the other needs that they may have that are under the HACC funding. Then as our resources increase or become available, we can then move over into the palliative care side of things.

I guess the clients still receive some palliative care, as in we still do a lot of our palliative care assessments on these clients, even though they are not palliative care. So we can keep an eye on their symptoms and keep an eye on their functioning and their functionality, so we can gauge when they are starting to decline and when their needs are increasing for more of a specialist palliative care input. That is what we try to do at the moment. If we do not have those resources and the client is quite stable and does not have a lot of symptomatic issues or the carers are coping okay, we would admit into a HACC service, and it might just be as a health check. So we can just go in to see how they are going, go through our assessments that we do and, as the needs increase, bring the palliative care specialist team on board.

**Ms SPRINGLE** — And can you perhaps talk a little bit about advance care directives and how widely they are used out here, if they are used at all?

**Mr WILLIAMS** — Can I just quickly go back?

**Ms SPRINGLE** — Yes, absolutely.

**Mr WILLIAMS** — To answer your question, absolutely people are not being admitted to palliative care. I think there has been a great shift away from just malignant patients to also non-malignant patients, patients with dementia, COPD and things like that. There has been a good shift there, but often those referrals are late. They are really at end-stage when those referrals are made. So in terms of framework I think that would be a great thing to build in — it not being a diagnosis-driven framework but needs driven, because people with COPD heart failure are having issues like shortness of breath and pain and fatigue, and these are things that we can be in there and helping them with, giving them the support. They just do not get it.

**Ms TURRA** — I do not think healthcare providers get it either. I think it is not unusual for even nurses within our own team to question a referral for somebody with dementia who has significant need, but they are not recognising that there is a need. Those people are entitled to palliative care, so there is a need for a lot of education with healthcare providers throughout, I believe.

**Mr WILLIAMS** — So education to the healthcare providers, but also to the families and the patients as well. Because with somebody with heart failure, we do not know where they are at in terms of trajectory because it is a difficult-to-predict terminal illness. Sometimes they hear the words ‘palliative care’ and they might think, ‘Oh, no, that’s not for me; I’m not dying right now’. But getting involved early and helping them with symptoms is what we can do, a year away. We can be involved a lot earlier in helping them to have a better quality of life at home, rather than bouncing in and out of hospital. So education for families and carers to let them know that palliative care is not a death sentence and they are there to help you.

**Ms TURRA** — I think, too, there has been an initiative within the aged-care sector, within aged-care facilities, through the Gippsland Regional Palliative Care Consortium with carers, around what is palliative care. When somebody does, I guess, fit those criteria, or depending on what their needs are, they are just as entitled as somebody living in the community — that is their home, where they live. I can think of three carers or family members in the last three years who have come to me and asked for help. I do not know whether it is because aged-care facilities are not recognising or they do not have the education or the knowledge that these people are suffering, and unfortunately it is not being managed appropriately. I think a lot of work needs to be done within aged-care facilities as well, because those people are just as valuable and entitled. I think people are not necessarily seeing that or they do not have the knowledge or the expertise, and a lot more work needs to be done within aged care — and disability services is well.

**Mrs PEULICH** — Thank you. My apologies. I had a couple of urgent matters to attend to, but I am fortunate in that I have the gist of your presentation. In particular what was of interest to me was your comment about inadequate education and information about what palliative care can do, what it is and what it can offer. We heard in earlier evidence today from a witness advocating perhaps more of a withdrawal of treatment or perhaps an even more robust regime — code for other options — but she admitted that she knew very little about palliative care. What can be done? Clearly the younger generation of medical personnel who are coming

through are coming out with a very different perspective of how to manage pain, so how can we actually get that information filtering through other service providers, including in hospitals? What can we do?

**Ms TURRA** — For me, it is starting with my children. I think in schools — and have a say in those discussions around death and dying as just a normal conversation that happens.

**Mrs PEULICH** — I appreciate that. Obviously raising awareness in the community is critical.

**Ms TURRA** — Yes. But within the hospital itself?

**Mrs PEULICH** — But in the hospital, because they are there at the coalface.

**Ms TURRA** — I do not know the answer to that, because we have ongoing conversations with different healthcare providers within the hospital, but there still seems to be a stumbling block. I will go, for example, into LRH, into an acute ward that provides palliative care as well as an acute service, and I will still have nurses who talk about palliative care being end of life. They do not recognise that palliative care is much more than just those last few days, and there has been enormous education and discussion within the hospital setting. I do not know where — —

**Mrs PEULICH** — Clearly not enough?

**Ms TURRA** — Clearly not enough, or is it because of people's own values and their own perception? That is a difficult thing to change. I am not sure, Luke, whether you have had experience?

**Mr WILLIAMS** — There is one thing. I do not want to get back to the resources thing, but there is no palliative care liaison in the hospital. That does not exist. Going back to my experience in Melbourne, every hospital had one. They were involved. You would just ring them and they would know who your clients in the hospital were, so they are advocating on behalf of the palliative patient, but that does not exist here.

**Ms TURRA** — And there is not that ongoing presence, that face, of palliative care.

**Mrs PEULICH** — Thank you. That was useful.

**Mr WILLIAMS** — That is something, but I think everything has been left really late. Maybe it does not have to start in the hospital but outside of the hospital and getting it into people's minds that we need to talk about these things. It is not the most comfortable thing to talk about, but giving people the education, the tools and the power to be able to have those conversations I think is really important.

**Ms TURRA** — And perhaps the GP is a good place.

**Mrs PEULICH** — But also maybe some of the seniors organisations. I mean, often they are call people into their meetings to talk about will preparation or whatever. Perhaps this could be one of those topics where if appropriate material and community educators are made available, you can actually continue to lift that awareness and broaden the understanding of what palliative care is.

**Mr WILLIAMS** — Yes. Everybody always thinks of a will, and there are advertisements on TV about funeral arrangements and things like that. I was at my Dad's house the other day. He has a bowel screening test kit. They are in-your-face sorts of subjects. It is going to happen to you, but there is no emphasis on talking with your loved ones just about, 'If something happens, this is what I'd want'. There is no emphasis on that. So even getting it out there, getting it on posters and in the mall, advance care planning.

**Mrs PEULICH** — You also have senior Victorians festival next month, in October. It would be one of the good things, to actually offer some workshops and seminars.

**Mr WILLIAMS** — Yes, absolutely, those sorts of groups and having people come in and do presentations about that sort of stuff. But it is not just old people.

**Ms TURRA** — I was going to say that.

**Mrs PEULICH** — No, that is right; it is not.

**Ms TURRA** — It is across the life span.

**Mrs PEULICH** — But you are just looking at how you can communicate the information to the greatest number of people for whom it is relevant. They will only tune in if it is.

**Ms TURRA** — Relevant at that given time, yes.

**Mr WILLIAMS** — But seeing things out there, posters and the like — —

**Mrs PEULICH** — Helps?

**Mr WILLIAMS** — Yes, absolutely. It gets it into people's minds. I am a young guy. My friends are tradesmen and they ask me what I do, and I say 'Palliative care'. That is a good way to get things into their minds, but it is so taboo that they do not want to talk about it. I will ask my mates how their jobs are going, but nobody wants to know about this palliative care job, and that reflects society.

**Mrs PEULICH** — It is still a taboo subject.

**Mr WILLIAMS** — It is, absolutely, yes.

**Ms TURRA** — I think, too, people have an expectation of the health system, that they will be cured, that they will be fixed, and that is a massive challenge. We have this increased technology, and now people's expectation is that when they go into hospital they will be fixed and they will come home.

**Mrs PEULICH** — That there will be a miracle.

**Mr TURRA** — Yes.

**Mr WILLIAMS** — Yes. That is a difficult thing to change because a doctor's job is to make you better, and outside of palliative care physicians I see a lot of them, particularly in oncology. They just want to keep going and keep treating. I met a young 48-year-old bloke this morning who is in a terrible situation and very clearly not going to get better, but in his mind he is. We could not open up and have those discussions because maybe somewhere down the line he is getting false hope. Maybe we need to be frank about what we are doing. It happens a lot, I must admit. Some oncologists are great and they are very frank, but sometimes we need to be.

**Mr MELHEM** — Just on that, you talked earlier about the gap between Melbourne and country, or Gippsland. Obviously there is a gap — it is a no-brainer that there is a gap — and it is something that I think successive governments will continue to work on and we need to fix that. In your experience — this is an inquiry about the end of life — do you see any need for changes to existing laws, for example? Is that an impediment to improved services or do we give Victorians a real choice about end of life, or is it just a matter of implementing the current system? If you do not know, you can say you do not know.

**Mrs PEULICH** — And funding it appropriately.

**Mr WILLIAMS** — I do not think in my mind that laws are prohibitive, no.

**Ms TURRA** — I think some of our clients perhaps would see that they are prohibitive.

**Ms SPRINGLE** — In what way?

**Mr MELHEM** — What is your view?

**Ms TURRA** — What is my view?

**The CHAIR** — And your clients' view, I think.

**Mr MELHEM** — And your clients'. Sorry, both, yes.

**Ms TURRA** — We have had occasions with clients that have been suffering so significantly that the question of euthanasia is always raised.

**Mr WILLIAMS** — Yes.

**Ms TURRA** — And that is a significant challenge. I can think of a few occasions when people have suffered significantly and they raised that. Currently that is not an option that is available to them. I think it is a really difficult topic. I definitely appreciate why people would like that choice. I guess I see the difficulty as around when that choice should be allowed, when is an appropriate time, and I guess who makes that choice. That is where I see it can become quite difficult and quite challenging. I also think the discussions I will have with somebody are ‘Currently it’s not an option, and these are the options; this is what we can do’. But I think people are looking for a choice. They want to have a choice, and currently there is no choice.

On my own viewpoint, I do not have a particular view, but I can definitely understand why clients and their carers are looking for that choice, particularly when someone is suffering so significantly. It is very difficult, as a carer particularly, to be there with their loved one and seeing what they are going through and knowing what the end result is going to be and there is nothing more anybody can do.

**The CHAIR** — If I could just follow up on that. Some have said to us in other locations where we have taken evidence that some patients or clients may have that view, but they do not appreciate what is the full suite of services that is available with palliative care. What would be your response to that? Do patients have a misunderstanding of what is available as far as pain management, pain treatment and services that are available, or is their fear legitimate and real and based upon the facts and the services that are available?

**Ms TURRA** — I think it is both. Here within this community we do not have the access to specialist palliative care physicians who have specific expertise in pain management, so that is a gap and an issue. But we have also had occasions where we have had input from specialist palliative care physicians on really complex pain. It has been very, very challenging, and that person has continued to suffer significantly. So I think it is twofold.

**Mr WILLIAMS** — It is not just the physical suffering.

**Ms TURRA** — No, it is the emotional.

**Mr WILLIAMS** — It is the emotional suffering. It is a 48-year-old guy who cannot get out of bed and cannot contribute to the housework, cannot do anything like that, so existentially he is — —

**Mrs PEULICH** — But does he want to die or does he want to live?

**Mr WILLIAMS** — Well, perhaps he wants to die.

**Mrs PEULICH** — To what extent are they influenced by the attitudes of those surrounding them, for whom he may be a burden? We have heard evidence today, for example, from one woman who has been working in the palliative care sector for 18 years, and she said that given the availability of medication through palliative care she would be surprised if anyone wanted to end their life but they did not have the medication to do so at their fingertips. So set that aside. To what extent do people feel burdened by those around them to make that decision?

**Ms TURRA** — Significantly.

**Mrs PEULICH** — To what extent do they feel pressured to make that decision?

**Mr WILLIAMS** — To want to die?

**Mrs PEULICH** — To die. Perhaps not personally want to die but to say, ‘Look, I’m inconveniencing my family to such an extent. I’m a burden’. It is a very Anglo thing in many instances.

**Ms TURRA** — I think that can be significant.

**Mrs PEULICH** — In societies where there is an extended family structure, where it is sort of understood that when parents are working, grandparents help with the children, and that is done with an implicit understanding that that is because you are actually investing in your aged care. There is this implicit understanding that the family will carry some of that load. I think there are cultural differences in terms of attitude towards those end-of-life issues.

**Mr WILLIAMS** — Yes, I think the feeling of burdening others is a big factor, but there is no medication in front of you to help with that. You cannot.

**Mrs PEULICH** — I guess the crux of it is: whilst in a democratic society people want to see choice maximised, what safeguards are there for people who are inarticulate, uneducated, who suffer from dementia, babies, people from multicultural backgrounds who do not understand, who do not want to see their mother go into hospital and be popped off as an accident or because there has been a lack of communication? Not only that, who can guarantee that at the point of facing death, even though you might have signed off on saying, ‘Yes, look, I want to be popped off if this happens’, who is to say that that person is not going to change their mind and want to live?

**Mr WILLIAMS** — I completely agree, yes.

**Ms PATTEN** — There is nothing to stop them changing their mind.

**Mrs PEULICH** — I think Holland shows otherwise.

**The CHAIR** — Is there anything more you would like to say before we conclude this session?

**Ms TURRA** — No. Thank you for your time.

**Mrs PEULICH** — It is a very difficult field. Thank you very much. We certainly appreciate the difficult issues that you have confronted.

**The CHAIR** — Thanks for speaking so candidly. As I say, the transcripts will be with you in the next week or so.

**Witnesses withdrew.**