

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

Dr Simon Fraser, Chief Medical Officer,

Ms Amanda Cameron, Acting Chief Executive Officer; and Director, Nursing, Midwifery and Clinical Services, and

Dr Tricia Wright, Physician, Latrobe Regional Hospital

The CHAIR — I would now like to welcome witnesses from Latrobe Regional Hospital. In particular I welcome Dr Simon Fraser, the chief medical officer; Dr Tricia Wright, a physician at LRH; and Ms Amanda Cameron, the acting CEO; and the director of nursing, midwifery and clinical services. Thank you very much for being here this afternoon.

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. Transcripts will ultimately be made public and posted on the committee's website.

We have allowed 45 minutes for our session this afternoon. I would invite you to make some opening remarks, and thereafter the committee will have questions. Thanks again for being here with us this afternoon.

Dr WRIGHT — Thanks for having us. We thought we would just start by describing what we do. I apologise. I did not hear all from community palliative care, but they form part of our activities at Latrobe regional health, so if I have said something to the contrary, tell me.

The CHAIR — That is not always a bad thing.

Dr WRIGHT — I guess in terms of palliative care at Latrobe Regional Hospital we would consider that to encompass all aspects of both outpatient and inpatient care for any adult patient, which is what I am talking about today, with a non-curable illness. This includes a malignant diagnosis. We have a fairly busy and active oncology centre, cancer centre, which is a fantastic service for the area. It also includes inpatient end-of-life care. So we provide essentially the hospice service for the region, in conjunction with our colleagues in aged-care facilities, for example.

In terms of the provision of that service for an inpatient population, that would occur through the general medical team. We are a fairly flat structure. All of our adult medical patients are admitted under a general medical team, so it is a fairly small group of physicians. There are four general medical teams as well as an oncology unit and we meet regularly. So there is a sort of group of people that talk about these issues frequently. Throughout the hospital we would consider that general medical team to offer the support and the services to other areas, so rehabilitation, the aged-care facility, intensive care, for example. We focus it there.

In terms of what we try to do to support that structure, there is a fairly active advance care planning program throughout Latrobe Regional Hospital, similar to many other public hospitals throughout Victoria. It is certainly the expectation that every adult patient admitted would have a discussion or a decision about the appropriateness of care for them. We are working hard to improve the outpatient services, probably starting in dialysis. That has been a very active area for some of our renal physicians, and we are certainly trying to work through that with our cancer care nursing staff in the cancer area. They are probably the two areas of focus in terms of support.

In terms of what exactly constitutes our palliative care team, we have a dedicated general medical ward. We try to focus on a particular ward, where patients who are receiving palliative care are admitted. In particular, a focus would be on difficult symptoms or end-of-life care. Luke and I had a conversation this morning about directly admitting a fellow from the community. We try to focus that directly in a particular ward, and obviously palliative care is operating everywhere, but for challenging areas it is one place.

Each week we meet as a multidisciplinary team — a group of dedicated allied health, nursing, community, palliative care — either chaired by me or by one of the medical oncologists who has training in palliative care. We talk about the inpatients who are requiring active palliative care. We work through those issues, and if there is a particular concern, then we will act on that. We do have within the region access to tertiary specialist palliative care services, and they visit the hospital once per month. They provide both an outpatient service as well as an inpatient challenging problem service, and we do have access to those physicians, as the community guys do if they need to call up for advanced specialist care.

We channel all of that work into a bimonthly palliative care working group. We are trying to respond to changes in delivery of service, anything that is happening, and that informs our executive team. We try to make it as flat

as possible and streamline all the information to one area. That can incorporate both the practicality of providing that service and making recommendations about how we see it, education programs, trying to develop policies around this area, and looking at policies that exist and seeing if we need to update them.

That is the service we provide. I have read a few of the transcripts and there has been a lot of discussion about different issues, but I thought I would just leave it to you to ask us particularly how we function within that structure.

The CHAIR — I might start in that context. I am particularly interested in your advance care planning program. What we have heard from some other health services is that there is no funding mechanism, and basically in the end health-care services have to make a decision to fund that sort of program internally out of the existing budget. I am just wondering if that is the same for LRH?

Ms CAMERON — There was funding initially for setting up the program. Then for the sustainability of the program the health service is responsible for embedding that in probably its work or its programs that already exist. From LRH's perspective, the advance care program sits within our health independence program. That group of nurses will be the people to follow up on the work.

The CHAIR — Have you modelled that on the Respecting Patient Choices program or is it something you have developed yourselves?

Ms CAMERON — It is not directly on their program but it has elements of their program.

The CHAIR — Is the fact you received seed funding for that but not ongoing funding an impediment to the rollout of the program, or once you embed it in your systems is it basically self-sustaining?

Ms CAMERON — I would not say that it is self-sustaining, but I do not know that it is because there is a lack of funding. It is more about the ability to educate and encourage people to have those conversations. The conversations are difficult conversations, so we continue to have education around that and how you have the conversation. I think that people are unsure when to have the conversation, and so there needs to be more work around that. There needs to be more work from a community point of view, from the fact that I think there is the perception that if we have that conversation, that means that people do not get treated, when it is not the same thing. It is actually just a conversation about your choices: if things do not go the way things are planned, how would you like things to be handled? I think that is quite an issue.

I also think there are some concerns around the fact that the conversations with the patient may not be the same as the expectations of their relatives and their carers, and so that can cause some impediments to having the advance care plan work as well as it should. We have only been, at LRH, doing the program probably for a year, so there is still a lot of work to be done to make it, as Tricia said, something that every patient would have as an inpatient. There is a lot of work still to be done for that.

The CHAIR — I just want to ask two more quick questions if you would indulge me. How many patients that you see would already have an advance care plan when they come into the LRH? Do you know?

Ms CAMERON — I would not know the exact number

Dr WRIGHT — After they have been admitted — everybody.

Ms CAMERON — But we do see some, and we have a residential in-reach program, which is a program that works into the residential aged-care facilities. They are trying to improve the uptake of the advance care plans as well. We do see some patients who come into the hospital that already have them. We have had occasions where they have had an advance care plan, and then there was the situation that I was talking about before where the relatives were not on the same page, so the advance care plan did not actually get completely followed the way the individual wanted.

The CHAIR — Just one other question too. We heard from an experienced nurse from the Central Gippsland Health Service earlier who talked about some of the challenges younger health professionals in particular have in talking about end-of-life issues, and we have heard that evidence from other parts of Victoria and from physicians in Melbourne et cetera. I am wondering if you would like to offer feedback about that?

Dr WRIGHT — I do not think that changes whether you are in regional Victoria, central Victoria or in the city. I think it is a big challenge, and Jenny mentioned about people coming to the hospital to get fixed. That is difficult — doctors being trained to fix people. I suppose one of the benefits we have here is, as I mentioned, that the general medical structure is flat and small. We talk about this all the time and we try to educate as much as we can, and people come from a whole variety of different areas. In my work it is something I talk about all the time, but for one of my colleagues who specialises in diabetes, for example, it may not be the topic of conversation that I am always talking about: the potential for treatment not to go well, treatment not to cure, end of life. I think that is certainly spread throughout.

In response to your comment about modelling Respecting Patient Choices, obviously it is fantastic that we have got a model to look to, but, as you have probably heard, there have been some concerns about aspects of that. I suppose we have a good opportunity to pick and choose the good bits, but certainly there is some concern about allocating this task to a group of people to wander around the hospital or outside to try to get advance care planning, because it is such a complex discussion. It is family, it is different physicians. Somebody might have three or four specialists with different input into their care. Some of it is complex. There might be new treatments available.

It is hard to make such a major document without all that information. I think that the intent was fantastic but it was probably a bit too much documenting everything as opposed to just a sense of how you would like your care to be as opposed to, ‘Do you want this or this or this?’. A different situation where people come into hospital where we can do absolutely everything, and generally we shouldn’t.

Dr FRASER — I would probably make a couple of comments from the medical doctor side of things. As Tricia indicated, we do have a very good group of very stable core physicians providing high-level leadership and engagement, but a significant proportion of our medical staff are junior, rotate from Melbourne and are here for a short period of time. That behoves us to ensure that we have ongoing education and reiteration about end-of-life choices. I think the other thing, though, from a medical perspective is it is a cultural change. Even though our physicians and I would say probably our paediatricians sometimes deal with chronic illness and with death and dying, some of our other craft groups still have a mindset at times that cure-all surgery is paramount. I think that is going to be a cultural and generational change.

Mrs PEULICH — Thank you, and certainly I think some of the initiatives that you have outlined that you have in place are quite possibly being replicated elsewhere. I am not sure whether you were here, Ms Cameron, but earlier I was floating the idea of an IT platform where an advance care plan — I do not know whether it can feasibly be eHealth that so few know about — that can respect different levels of privacy and can trigger the sending out of relevant information to a patient or someone who may have triggered or made inquiries about particular services.

People have access to lawyers who prepare wills for them, well in advance of them needing them hopefully most of the time, and funeral planning. Women who are over 50 have free breast screening. Would it not be feasible for perhaps some sort of investment into developing an IT trial that works through doctors and can perhaps look at funding or underwriting, say, people who are over 55 or over 60 or whatever spending some time with their GP in order to prepare an advance care plan. That then sits and is shared between the relevant providers with due respect to privacy. Is that 21st century fantasy, or is that something that would actually make life easier?

Dr WRIGHT — I guess the GP team do that in terms of complex care plans. I would imagine that doing an extra thing on top of what is already there perhaps is not — —

Mrs PEULICH — I was actually thinking of bringing it earlier, so they were coming into hospital with some of that thinking already done.

Dr WRIGHT — Yes, I was just saying that people come to a GP and have a complex care plan developed so that they can make sure that they are ticking through their diabetes, ticking through this and ticking through that. That seems to work pretty well. Obviously there is some financial incentive for the GPs to do these complex plans, and perhaps adding it to something that is already working — you probably heard from the Austin, where they attempted to use their computer system so that there would be alerts whenever somebody came in with an advance care plan. That is great, fabulous, but they fall through the cracks sometimes as well. I am not sure. I think there is certainly great opportunity to use our IT and systems that are in place to incorporate

this. I am not entirely sure about how making stand-alone individual advance care plan platforms would be effective if there are some — —

Mrs PEULICH — I do not think it could be stand-alone. I think the benefit of that would have to be that it is integrated.

Dr WRIGHT — Yes, sure. I think that is true. I suppose that critically we have not even got the basics done. We are still, ‘So, your regular medications?’, then tick, tick, tick and this sort of thing. The IT systems are different. Everybody is trying very hard. The pharmacy has a different system — —

Mrs PEULICH — Same story everywhere in relation to everything. We have done a number of inquiries looking at health and wellbeing. Local government collects different sorts of indicators, they are not integrated with central indicators, there is no compatible system of IT. If we were designing these IT systems now, we would do it with those points in mind, but it does not mean that we should not look forward.

Dr WRIGHT — No, of course not.

Mrs PEULICH — I know that in the Justice department — and I think Ed in his former portfolio may have been responsible for this — at Moorabbin police station they had a triage system operating where relevant agencies, such as the mental health association, housing agencies and so forth, were notified of people when they had these chronic problems that saw them re-present at the local cop shop and interface with the police. We have got to be looking forward.

Dr WRIGHT — Absolutely, and I guess with your comment about is funding adequate: no. We would need funding. It is all very well to say, ‘Here is the new system’, but the implementation and trying to work it into your own takes so much more training and you discover that you need several different policies to integrate a variety of things, and then you need a patch and you need the IT person to come back. I think there are always great intentions and people do get some fantastic services and then we do not use them as well as we could because we run out of the basic implementation program. I have seen that in many health services.

Mrs PEULICH — Dr Fraser was going to make a comment?

Dr FRASER — Yes, I was going to say that I think this can only work with a national record — —

Mrs PEULICH — At a national level.

Dr FRASER — Certainly one of the points I was hoping to touch on is the importance of integration between health services in Victoria — community health services, general practitioners and the home. It is frustrating and disappointing when you have a process in a hospital where if you do not know, we will always resuscitate — we have to — only to find you are embarking on a course that perhaps is against the individual’s wishes that you did not know about. I think that the vision you have needs to occur.

Mr MELHEM — Following on from that, if we look at the current medical practices about how people have access to real choices about end-of-life choices or know their rights, I suppose, how do you balance their rights versus a conflict with, say, family — there are always arguments — and doctors’ beliefs about being there to save lives? How do you balance all that?

Dr FRASER — I would like to tackle that because I think it raises that fundamentally the individual’s autonomous choice has got to take priority. I think that comes first.

Mr MELHEM — What do you do to enforce that?

Dr FRASER — I think it is perhaps a bit of a catch 22, but you need to know, if you can, prospectively what their individual choice and desires are. I think that has to be respected. I remember being taught 30 years ago in medical school about the controversy of termination — that at the end of the day a doctor’s role is to respect the choice of the individual, even if that is at odds with the doctor’s own values. I am not sure if that is what you were getting at — —

Mr MELHEM — Yes, tease it out.

Dr FRASER — Yes, and I think it raises an important issue. If we are talking here about euthanasia, which I think is what you are referring to — —

Mrs PEULICH — It is code.

Dr FRASER — Whatever code you wish to use. I think there needs to be legislation to ensure that doctors are involved in the process if they choose to be involved, are protected, that the process is safe and that there is an opportunity, as you have indicated, if an individual changes their minds for them to be able to change their mind.

Mrs PEULICH — My concern is for those who do not get a chance to express their viewpoint and it is made up for them, whether it is by family or those medicos.

Ms CAMERON — I think there are probably ways you can get around that.

Ms SPRINGLE — Which probably segues into my question: what is safe? You mentioned if it is safe. What is safe to you?

Dr FRASER — I guess I am referring specifically to safe from the doctor's perspective.

Ms SPRINGLE — Legal proceedings.

Dr FRASER — That a doctor is in an environment of legislation where there are safeguards, adequate training and double-checking, ensuring there are no pecuniary interests et cetera. That a doctor, if involved in end-of-life choices, is legislatively protected.

Ms SPRINGLE — Yes. In terms of safeguards, do you have any thoughts around what would be appropriate safeguards for doctors in that situation?

Dr FRASER — I think it would have to ensure that there is a second opinion; that the doctors involved in the decision and even prescribing medication are not the active treating doctors of the individual and are not in any way related or have any pecuniary interests — and possibly even have the training and the credentialing to do so. In other words, they are small group of doctors who have the understanding, the ability and the checks and balances to be completely effective.

Ms SPRINGLE — On that, as Mrs Peulich has just indicated, what about safeguards for the patient in terms of coercion and other like scenarios with family members or people who are carers?

Mrs PEULICH — Wishing to create a greater turnover in beds with an ageing population.

Dr WRIGHT — I think most of the questions about consent that you are raising are actually happening right now. I do not think that thinking about 'the pill' actually changes this in any way

Ms SPRINGLE — Can you elaborate on that?

Dr WRIGHT — I do not want to sound like I do not completely agree with my chief medical officer.

Mrs PEULICH — The individual viewpoint you did say was the most important.

Mr MELHEM — You do enjoy privileges — —

Ms SPRINGLE — In here that you do not out there.

Dr WRIGHT — I completely respect every single one of my patients but I also am very clear that there are some medical decisions that I will make with them and in some instances on their behalf; for example, resuscitation and intubation. When people say, 'I will have the works, thank you very much', and I think that that would be inappropriate, I will talk them through that. Families regularly will say, 'Don't talk to mum. Don't say cancer. Do not say those 'c' words. Don't say this'. I will say, 'If you could sit in with us and let me start the conversation, we will see where we go'. And 99.9 per cent of the time, before I finish the sentence, their mother will say, 'Have I got cancer?'.

By modelling that behaviour we are trying to train our junior medical staff. Every one of the seminal moments in our training has been, 'I remember when Professor Blah Blah talked about something challenging and we watched how he did it', and you take a little bit of that. I think we play an incredible role in making those decisions right now, and it is about encouraging people to talk about it. The safeguard is that most of the medical profession actually wants to cure and do absolutely everything and we are saying, 'Come on, let's have a think about it', so in terms of going too far, that is the major conversation that we have. Are we treating too much? Have we gone too far? Are we thinking about this properly?

Family members are concerned about losing their mum, about doing everything, so if we can take responsibility and say, 'We are doing everything, just not those three things. We are not going to do those three things because they will result in broken ribs and trauma and terrible situations and that will not be your mother you will be sitting next to'. They are the conversations we are having now, and if there was a change in legislation, I think we have got a system in place that it would be integrated.

Ms SPRINGLE — You have it or that is industry-wide — —

Dr WRIGHT — I think the medical — —

Ms SPRINGLE — It is an industry-wide thing.

Dr WRIGHT — Yes. And there will be people who say, 'That is not something I can do; I will not do that. This is something that I can do; I will do that'. We will develop a training program if that is required or a certification program if that is what is indicated, but I do not think there needs to be. There is the fundamental practice of medicine and it seems to have worked pretty well for several hundred thousand years.

Ms CAMERON — If I could comment about that in relation to when we first started talking about brain death in intensive care. These were the similar types of conversations that occurred then and the similar type of fears that occurred then, and that has not developed. That has not occurred. There were checks and balances put in place around when someone is certified as brain-dead, and they have worked very well. They have worked very well for quite a period of time now.

Dr WRIGHT — Just in response, I think you mentioned something about this fear that older people are moved around because of the bed pressure. Certainly in the palliative care forum we have learnt many lessons from Europe in terms of that. When they put in the pathways there were concerns because exactly that happened: people were put on pathways too early. So as a professional group we are always responding to best practice and information around the world and feeding that back. We had a conversation about that in our palliative care working group recently.

Mrs PEULICH — I understand your comments and appreciate your comments and appreciate the difficulty of your job. We heard earlier about the bargaining, the exchange of information, the shift in values, the shifting perspectives of people who are facing death and so forth, wanting to see out the next milestone. I guess my concern — coming from a multicultural background and knowing the difficulty of language — is for in particular people who may be functionally illiterate in their own language. I would not entrust a difficult conversation to my mother, even though she has been here for 45 years, with a medical practitioner without me being present.

My concern is that, apart from dementia patients, those who have suffered brain injury, the inarticulate, the babies, people from multicultural backgrounds or functionally illiterate, or even people who are not — there are people who want access to euthanasia on the basis of experiential pain. The Holland trial has seen that 1000 people were accidentally euthanized following an audit after five years. How can you put in safeguards for all of those, for the inarticulate in particular?

Dr WRIGHT — I think that we are having challenging conversations with people like your mum that you describe all the time, and we would never do that in isolation. Yes, it is true that people come in on their own but there are three or four phone call follow-ups afterwards. I feel awful when somebody comes to see me in an outpatient on their own. It is the worst situation I think I can be in and people are asking permission, 'Do you mind if my ...'. Of course, bring everybody in. When people bring their family in that is when I feel more comfortable about these challenging decisions.

I suppose the answer to your question is never, but we do it all the time, for many, many challenging decisions all the time. We have some basic principles about how we approach this, and it is a difficult situation where there are concerns about competence et cetera. We probably do not do it as much as we should from a medical perspective, but we rely on our nursing colleagues and our allied health colleagues, meet regularly, have multidisciplinary meetings and talk about it so they can say, 'Actually, you have got it wrong. You said all that. They nodded. They came out here and told us a different story'. We cannot practice in isolation any more. We have made that very clear.

Mrs PEULICH — We heard earlier a witness saying that patients are regularly lying to their doctors.

Dr WRIGHT — Yes, of course.

Mrs PEULICH — That might be the case, but who is to say the patient was not regularly lying to her as well?

Dr WRIGHT — Yes, sure. Human nature is interesting, it makes our job interesting. These challenging decisions happen in our oncology setting, so you start at the beginning, you talk about what the process is, there is an education session with the nurse, there is allied health available to go through. We talk about it as a multidisciplinary area, people tell us what we got wrong in terms of the family dynamics. We work through it again. We do our best in terms of, 'This is the best treatment we think is available for you', and then we take it from there. Practising medicine in isolation is not what we do anymore, and none of the nursing staff would let us do it even if we tried.

Dr FRASER — I just wanted to touch on an issue we have not raised yet, and that is children. Tricia specifically commented on adults. My other role is I am a paediatrician and in fact I have a background in neonatology, so the management of preemies and newborns and palliation and death is something I have had quite a lot of experience with.

It is a different area in relation to the position of a child or a baby in a family, particularly early in life where you lose the hopes and dreams of what you expect. Certainly in Melbourne at the three perinatal centres and the Royal Children's Hospital I suspect end-of-life management involving children and babies is done well. I do not think it is done very well in the country and I think that is because we do not do it very often. It is a brave paediatrician who, faced with a newborn baby who is clearly severely asphyxiated — using a medical term there — or where it is clear that the baby is not going to survive, will make the decision in conjunction with the transport team to keep the baby in a regional setting. Often because they feel uncomfortable about dealing with death in babies. You often have this situation of displacing the baby and their family to a tertiary centre. I think that is an area that needs work, and I wanted to comment on it.

The CHAIR — In that they would be better to stay in the regional setting?

Dr FRASER — Yes, I believe so. But you need the education and the support to be able to do that.

The CHAIR — Any other questions? Before we wrap up, I invite one of you — I represent this area so I have got a good understanding of what LRH does, but perhaps just for the benefit of committee and for the transcript — to describe the breadth of the geography and the services that LRH provides.

Ms CAMERON — Okay. I suppose that is my role really. Latrobe Regional Hospital provides both local services to the Latrobe Valley but also provides regional services to the region of Gippsland. We cover all areas. We cover acute, subacute, aged care, mental health — we are the providers of mental health for the whole region of Gippsland. We have the inpatient mental health beds here and then we have eight community mental health areas across the region as well. We also have intensive care. We offer a wide range of acute services. We have a cancer care centre with oncology, and we have support from the William Buckland Centre at The Alfred to provide radiation therapy as well. We have the first mother and baby unit for the region, which was only opened 18 months ago to assist with not acute postnatal depression but with a more subacute level, which has been well utilised as well.

We are the biggest employer in the region. We provide regional services as far as the cancer care centre, rehabilitation at a level that is regionally and we also provide orthopaedic services here for the region. We have

a comprehensive obstetric maternity area that has a special care nursery that can take babies down to 32 weeks — anything under that goes to Melbourne. Is that enough?

The CHAIR — That is great. Thank you.

Ms CAMERON — I can talk for a long time about the hospital.

The CHAIR — It just gives a perspective on the breadth of services you provide. To the three of you, thank you very much for your evidence today. As I said in the introduction, the transcript will be with you in the next week or so.

Witnesses withdrew.