

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Shepparton — 13 August 2015

#### Members

Mr Edward O'Donohue — Chair

Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

Ms Fiona Patten

Ms Margaret Fitzherbert

Mrs Inga Peulich

Mr Cesar Melhem

Ms Jaclyn Symes

#### Participating Member

Mr Gordon Rich-Phillips

#### Staff

Secretary: Ms Lilian Topic

Research assistants: Ms Annemarie Burt and Ms Kim Martinow

#### Witness

Ms Carolyn Hargreaves, After-Hours Hospital Manager, Goulburn Valley Health.

**The CHAIR** — I declare open the Legislative Council’s Legal and Social Issues Committee public hearing in relation to the inquiry into end-of-life choices. I would like to welcome Ms Carolyn Hargreaves, the after-hours hospital manager from Goulburn Valley Health. I thank Ms Hargreaves and her team for hosting us here today. It is much appreciated.

Before we start, I will caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today’s evidence is being recorded. You will be provided with a proof version of the transcript within the next week. The transcripts will ultimately be made public and posted on the committee’s website. We have allowed half an hour for our session this morning, so I invite you to make some opening remarks and thereafter the committee will have questions.

**Ms HARGREAVES** — Thank you. My name is Carolyn Hargreaves. I am one of the after-hours hospital managers here at Goulburn Valley Health. I am also the nurse donations specialist for organ and tissue donations, so that is another big interest in end-of-life discussions.

As an after-hours manager frequently dealing with families facing some decisions regarding end-of-life choices, that is really one of the biggest issues: those sudden choices. The biggest issue is having family members who have not made their loved ones aware of their end-of-life choices and who do not have an advance care plan. What they really need is ongoing communication with hospital teams, and that is sometimes where we really struggle — with ongoing, consistent communication with multiple hospital teams. Sometimes we do not have a really clear approach and pathway to end-of-life discussions with families.

Within the field of organ tissue donation, we have specific family donation conversation workshops where staff are trained so that there is a consistent approach and a consistent language when we are speaking with families in those types of situations. Sometimes that is not transferred across to when we are talking with palliative families, and that is something that I think could be really helpful — to have that consistent language and consistent approach right through the process with the families.

Sometimes when we are speaking with families we are really focused on the ongoing intervention in the current issue as opposed to the outcomes. When you speak to families it is really difficult for them to understand or make a decision about an intervention that they may or may not want, but what they do clearly know is what kind of outcomes their loved ones want to go home with or will be happy to live with. That is sometimes not what we focus on, and I think that is something we need to be able to focus on a bit more by having consistent family discussions and consistent training in that area right across the board.

We know what the World Health Organisation’s definition of palliative care is and how it is looking at the pain — the physical, the psychosocial and the spiritual aspects. I think we sometimes get the pain and the physical aspects okay, but supporting the psychosocial and spiritual aspects is something that I think we really need better support in working through — basic things for families, really good space for these families to be supported through as well. In hospital settings that is sometimes just not possible. That is the outline of what I wanted to discuss.

**The CHAIR** — Thank you very much. Just by way of getting the questions going, do you want to give us some more background as to how you deal with the challenge of communication, as you said, with multiple hospital teams often involved with the patient and what learnings you have from that?

**Ms HARGREAVES** — Starting with the emergency department, it is really important to identify one staff member — and sometimes it is up to the after-hours hospital manager, who is going to be there for the next few hours — who is going to be with those families for those conversations, because in that rushed initial phase there are multiple people coming in with really tight time frames giving people lots of information. You see a doctor or somebody walk out of the room, and these families just have this blank look on their faces, so you are often interpreting what they are saying and explaining further.

We know these traumatised families need a lot of time to understand what they are being told, and they often need to be told multiple times to get that understanding simply because they are in that traumatic phase. Having someone consistent to be there with the person is great, but sometimes it cannot be like that. The reality is that they then go from one department up to the next department and onto the next department. Sometimes that

medical team can be the same, but sometimes it changes as well with on-call and all those kinds of things, so they are getting lots of different interpretations and presentations of what is going on.

**Mrs PEULICH** — Shepparton is quite diverse — I would imagine more so than many other country and rural or regional areas. Could you explain how the challenges of language and culture present an additional overlay of considerations for you in that role? Are there cultural differences to the attitude of death that make an even greater challenge? Could you explain some of that and how you deal with that?

**Ms HARGREAVES** — First of all, how we support families that are of a non-English-speaking background: we really have interpreters over the phone. We can always access them, but it certainly is not great. Often we are reliant on family members who can speak English. That is very difficult. As you are going from one department to the next department, especially in those initial phases, that can create some really big issues. Family members are great as interpreters, but you cannot be assured that what the family is receiving is exactly what is being said. That is challenging, and at the moment a big thing in those initial phases is using phone hook-ups.

Regarding death and dying and being culturally aware, I think it is back to those really good skills of understanding and listening to what the family members are directing you to do and what they believe is acceptable. I think that with any cultural group there are always differences within that. We need to listen to what they are telling us. Do we have a set way of doing that? We probably do not have a set way of doing that, but I think that with good communication we do do that.

**Mrs PEULICH** — Are there differences in attitudes to death between, say — —

**Ms HARGREAVES** — There certainly are, yes.

**Mrs PEULICH** — Could you perhaps tease some of that out a little bit?

**Ms HARGREAVES** — Often it is about interventions prior to death, the process after death and time frames. Some cultures want people buried within a certain last-time viewing of the body after having people present with the person. Even having smoking of rooms in some cultures, we have been able to provide that kind of thing as well.

**Mrs PEULICH** — How about pre-death? A number of us come from multicultural backgrounds, and simply talking about death is almost like surrendering to death. That, I think, is the biggest challenge.

**Ms HARGREAVES** — That is right. There are challenges in even informing the person who is dying. Some families from different cultures do not even want the person who is dying to be informed as to exactly what is going on. Again, those challenges do come up, and they are just ongoing discussions. I guess we do not have a set way to get through that; it really is just an ongoing discussion with the family.

**Ms SPRINGLE** — I am keen to hear a little bit about what sort of advance care planning there is in your facility and if you think it is adequate for the needs of the community.

**Ms HARGREAVES** — I would not be the best one to specifically talk about advance care planning here. But it is still relatively new, and that is probably our biggest issue. We are still trying to get a lot of people to go through that process. I guess that is probably one of our biggest challenges here.

**Ms SPRINGLE** — When people present is it something you have to ask for, or is it something that generally people will say they already have?

**Ms HARGREAVES** — If they have one that is with our hospital, it comes up on a flag, so we know straightaway that there is one there.

**Ms SPRINGLE** — And if not?

**Ms HARGREAVES** — If not, we do ask.

**Ms SPRINGLE** — Right, thank you.

**Ms PATTEN** — Thank you for that presentation. I was interested in the donation side of this, because it seems that the community has become quite well educated about making that donor decision. If you have someone who has made a decision about organ donation, yet they do not have an advanced care or refusal of treatment plan, do you find that that contradicts itself, so you are ending up treating at all costs, which may put in jeopardy their plan for donation?

**Ms HARGREAVES** — There is a heightened community awareness, but we still know that at the moment only about 60 per cent of people have had that conversation with their loved ones, so there is a disconnect. One of our biggest challenges is that when you are speaking to the families the biggest reason they say no is that they have not had that family conversation. Again, it is reflected in the advance care. If only 60 per cent have had that conversation about something that we are putting a lot of effort into community awareness about, that can sometimes be a shorter conversation than what an advanced care plan is, which is much longer and much more in depth. If we have only 60 per cent doing this, it is probably reflective of the fact that less are probably having an advanced care, more memorable, conversation, I guess. There was another part to your question, I am sorry.

**Ms PATTEN** — It was whether with not having that advance care, particularly with that 60 per cent that have had the donation conversation, that puts in jeopardy their donation decisions.

**Ms HARGREAVES** — It certainly does. One of the biggest reasons why people say no is because they have not had the conversation with their loved ones, so come that really traumatic time, they just do not know. We support families through making those decisions; we reflect on what the person would have wanted. We are trained to have those long conversations — and making sure that the families are really comfortable. If it is a no, that they are comfortable with that no six months down the track, and if it is a yes, they are comfortable down the track. An informed yes or no is what we are looking for. I guess what I am saying about that, about speaking to families about that, if that was reflected across to advance care planning, which it is to an extent, about getting the advance care planning done, but having those conversations with those families at that time, if we had those consistent sort of approaches, I think that that would be very helpful, too.

**Mr MELHEM** — In your position, what sort of changes would you like to see in relation to giving people better choices in relation to end-of-life choices?

**Ms HARGREAVES** — I think providing families with a better understanding about realistic outcomes. We are often talking about interventions, what we can do right now, but when you are speaking to families and aggrieved families, especially reflecting back on organ donation, when you are talking to them, you have the opportunity to spend a lot of time with these families. What they are really talking about often is what they would have wanted, what they would not have been happy to live with. They have had the time to reflect and they think about that end.

When families come in initially we are talking about interventions right now, to stop whatever process is happening right now. We do not tend to focus on: what does that mean when the person leaves the hospital or two weeks down the track. It is much more of a focus on, ‘If we do this intervention, it may mean prolonging something for a week or a month, but it may not, and if it doesn’t, what does that mean?’ — some really clear communication with the family about those kinds of things. It is really hard for these families that sudden events happen. You have probably heard these figures before, but if you are given a one in a million chance if we do this intervention to help your loved one, they will take it. If we actually sat down and really went through what that means, they may not, when we really look at what the intervention outcomes can be.

**Mrs PEULICH** — Carolyn, just on that score and coming back to my multicultural demographic, some of them have come here surviving one in a million chances. Your telling them that that is somehow not good odds is hard to take.

**Ms HARGREAVES** — Absolutely. That is right. When you are not empowered to make that decision, then you are just going to go with it. It is really hard to get that clear conversation about if that does not pay off, then what are the outcomes going to be.

**Ms FITZHERBERT** — I have a couple of questions. First, I was interested in what you said about consistency of language. Could you give us a practical example of what you mean? I think I know what you mean; I just want to make sure that I do.

**Ms HARGREAVES** — With organ donation we have a consistent approach. We practice how we approach families, so we get to play with those words in our mind. We get to feel how comfortable they are speaking to families about that. We learn how to check in with families and make sure that they understand what we are talking about. We are using consistent language because we are looking at what are sometimes the better words and better language to use, whereas when it comes to end-of-life discussions and ongoing discussions with families, there is just really the approach from each individual, so maybe less consistent. As they are being approached and spoken to by different staff, that is going to change, too.

**Ms FITZHERBERT** — You have spoken of how often there are not discussions within families about end-of-life issues. In particular when there is a traumatic event that suddenly happens, I can understand how that may not have happened, but I imagine you deal with other people for whom it is not a sudden traumatic event that is leading to death. In your view, and this is something we have talked to other people about, is there a way that you could have an intervention earlier or a trigger point where a discussion of some sort might happen? Is that something that you think would be useful? How would that work? Is that something that comes up in your work?

**Ms HARGREAVES** — We have advance care planning, and that is great for people who have the opportunity to have the advance care plan. But even if they have an advance care plan, another incident may happen that leads them to a hospital stay and that may be where we need a different type of plan. We talk about advance care planning; what about more an inpatient-type care plan? That could be very different. If they do get to go home, it could be additional to the advance care plan, because now we are talking about this immediate incident and then if they do go home, what is going to happen next? So along the same lines as an advance care plan but a next step to it. Looking from way back here about what can happen in the future, that is great, but now that something has happened, or something has happened slightly different to what is in the advance care plan, then a new, more in the time of where we are care plan. If that makes sense.

**Ms PATTEN** — Ms Hargreaves, you were talking about the problem in the situation where a patient is going from one team to the next and that lack of communication going through there. I guess I am reflecting on the fact that with the donor system you have got the language there, so we can consider whether we can use that process. Is there a process where the donor communication goes from team to team? Have you got a system in place for that?

**Ms HARGREAVES** — I guess probably the difference would be that they are dealing with one or two people through that process. If they have come into hospital, someone like myself would be involved to speak with the families, and then coordinators would come up from Melbourne. So it has got the luxury of being only a couple of people, as opposed to somebody who presents to the emergency department, who has the AO see them, then the registrar, and then they go maybe to intensive care or to the ward. On a weekend they will have only one team on call, so they have got a separate team come Monday. So I guess having a flag with these patients that we are looking at end-of-life care and having a group or a couple of people who are able to support them through that process.

**Ms PATTEN** — Because obviously that flag must come up for the donor scheme to operate?

**Ms HARGREAVES** — Yes, absolutely. As soon as they fulfil the criteria, then it is referred and someone like myself would become involved, yes.

**Ms SPRINGLE** — You talked about this idea of an immediate care plan as opposed to an advance care plan, and that is slightly different from the understanding that I have heard from other people we have seen who have testified from the health sector, in that their practice, their understanding, how they use the advance care plans is like a living document which actually changes as the person progresses through the stages of their health. Is that something different to what you are talking about? It seems to be a little bit at odds with what we have heard before.

**Ms HARGREAVES** — Yes, and it is there like that, but making it work, I guess, probably. It is almost like it is sitting there but I guess making it work more.

**Ms SPRINGLE** — In what way?

**Ms HARGREAVES** — So that then if they are coming in with something that is separate to what they were diagnosed with — a cancer — and that is what they have based their advance care plan on and they have come in now with something completely different, like a bleed, then having it sort of continue on, I think there is a disconnect with having that continue on to a discharge and further one.

**Ms SPRINGLE** — In terms of the concept or in terms of the practice?

**Ms HARGREAVES** — I think the practice.

**Ms SPRINGLE** — That clears that up for me. Thank you.

**Mrs PEULICH** — Just a point of clarification. I am comforted by your answer. If there is an advance care plan in place, it is not going to be used as a coverall for anything that happens; is that right?

**Ms HARGREAVES** — Yes; that is right.

**The CHAIR** — Ms Hargreaves, thank you very much for your time this morning and for your evidence. As I said, a copy of the transcript will be given to you in the next week or so.

**Witness withdrew.**