

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Shepparton — 13 August 2015

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#### Witness

Mr Vin White, Nurse Unit Manager, Intensive Care Unit, Goulburn Valley Health.

**The CHAIR** — Welcome, Mr Vin White, the nurse unit manager at the intensive care unit here at Goulburn Valley Health. Thank you very much for joining us today. Before we start, I caution you 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. Thanks very much for fitting in with our schedule this morning. We have allowed half an hour for our session, so I look forward to hearing what you have to say, and thereafter the committee will have comments.

**Mr WHITE** — No problems. End-of-life intensive care does not always sit well with end-of-life, but we actually do encounter it quite often. The unfortunate side is that we have high-tech technologies which can extend and prolong life and sometimes it is fairly hard to know whether you are prolonging death or providing opportunities to recover and get better.

I think one of the very first things from my perspective is that the community does not actually engage well in a conversation regarding death and what people's wishes are. When patients rock into emergency departments and stuff, the family members might actually say, 'Oh, they're really well; they go out into the garden and work', but talking to them, they are actually not as well as they made out to be. Whether the family is aware of it, whether the patient is actually hiding it or accepting things, that conversation is not always there. It is more rare that it is there, probably. Right from the word go when people present to hospital, we have an impetus to treat people when they get here.

There is a time pressure to get people in and out of the ED. We have the targets to try to make, to assess patients, make plans and get them out of there — 4 hours. You cannot get a conversation going in 4 hours, so quite often patients are admitted to the wards with no treatment plan for the terminal diseases that they might have. Unfortunately, quite a few of those might arrest or run into troubles. We have all the track and trigger tools and stuff to highlight to staff to actually escalate the concern. New calls come to us, we might go out to the wards and review the patients, and that is when a treatment limitation order comes in, because they recognise that the patient is pretty crook, that they have terminal diseases, they have stuff like that and if we try to do stuff we are actually just going to prolong things. Sometimes it is about providing symptom relief and just keeping them comfortable and having a good conversation with the family members who are there or sometimes the patients, if they are cognisant enough to actually understand what we are talking about.

It would be really good if that conversation could happen in the community. I do not think it is actually done that well. When they hit the hospitals, especially in regional areas, sometimes it is the quality of the medical staff they are actually dealing with. Are they very junior doctors? Are they recruited from overseas? Sometimes they do not want to make decisions of major consequence, so they decide not to make some decisions or not to discuss things and that might lead them into — they might feel they might have less trouble, type of stuff.

We also have a variety of approaches. As individuals, the doctors and nurses bring their own morals and ethics into a bit of a conversation — the engagement with the patients, as well. We do occasionally see, if a person comes in on a weekend, one medical team that is covering the hospital for the weekend put in a plan for end-of-life treatment, palliative care, symptom relief, whatever. Come Monday, the home team, with the doctor who is there to look after them, comes back in and changes the plan again.

The families themselves then start questioning: who do I trust? I have this bunch of people here saying this, one thing; another bunch saying something different. I suppose what we try to do for us when we are faced with that is we say, 'Well, here's what we're looking at'. We show them all the blood tests, we show them this, that, and discuss what is normal and try to work with them. We try to work with the family significantly if we cannot engage with the patient as such. That part of it is where it gets fairly difficult.

I think we are very fortunate here to have had good community palliative care. Only recently is it now actually stepping into the hospital. But we still at present have not had full medical staff engaging in it. One doctor might not refer their patients to palliative care, because they want to manage it themselves. I suppose what we are looking at is the expert group. They can put the patient onto therapies, to issues or contacts — families into support groups — that their doctor might not actually be fully aware of or that they extend to. We are actually just starting, even in intensive care, to work with Annette — she comes in a few times at present — so it would be really good to further develop that. We could almost have it that if someone is on that pathway, we have to

do it, rather than leaving it to the consultant to make the decision to do the referral. It would be good if it was automatic — no health bar, you just do it, and then work as a team, not fighting against each other. It does not always happen. Egos come in the way sometimes — and stuff like that.

Patients sometimes actually get discharged. They do not all die, so they go out. The other thing is does the hospital fully inform the GPs with: this is what the treatment has been, this is what the plan has been, these are our discussions with the patient, and can they take over the footy and work with the patient along these goals. We do not want to reinvent the wheel, which does happen sometimes. When the patient comes back to hospital at another time, we start over, we look at their treatment limitations order afresh. Even though they have been well known previously — you find the previous orders in the history and stuff — we start afresh again. So we do not always do things that well.

Sometimes, as I think one of the people said before, if there is an issue there the family sometimes get lost on what they can do and stuff. One of the first things is to dial an ambulance and call for someone to come and give them a hand. The ambulance is designed to treat. They have their algorithms to follow. Part of their job, if there are respiratory problems, is to intubate; drugs — get them into hospital and do stuff. It might not be in really the best interests of the patient. It is an interesting area.

**The CHAIR** — Thank you very much for that evidence.

**Ms PATTEN** — Thank you, Vin. I think you were certainly reiterating what Ms Hargreaves said earlier about that need for constant communication and for everyone to be on the same page. Another matter raised by some witnesses in ICU that we have spoken to was about looking at palliative care in ICU and providing the medication. They said that some nurses were nervous about providing high levels of opiates or pain relief that may subsequently hasten death. Has that been raised with your team or is that a concern in your team?

**Mr WHITE** — ICU here, no, it is not. It is a privilege, actually, to give people as comfortable a death as you can. I think that is one of the really good things I get out of nursing. It is a terrible time for the family and it is about how much support you can give them. I think we actually tend to do it fairly well. We have had a lot of families, even after the parent or someone has passed, come back and thank us and drop in gifts and stuff like that as a thank you. So from that point of view it is good.

It is all about keeping the person as symptom free as possible. You cannot always make them pain free; you cannot always alleviate all symptoms. It is about trying to do the best you can and it is working with the family as well. They can pick subtle changes when they can say, ‘This person is actually in distress’. We might not always see it because sometimes we use monitors and stuff. The family has known that person for a long time without us being there, so they might actually pick up on some subtle changes that we might not. If they do let us know, we do stuff. We are actually trying to treat symptoms. If they inadvertently hasten death, that is just one of those consequences. We are not directly doing stuff. But it is about trying to work with people as best we can, and if it takes high doses, it takes high doses.

I suppose I was fortunate to help palliate my dad at home, and the hospice team left a fair amount of stuff with us. I was giving what I would consider were fairly horrendous doses — if it was someone else in a different setting — but that is what it took to keep my dad comfortable, and I think most of us take it such that, how would we want to be treated? Would you want to be put through the ringer? No. You want to be comfortable, and by doing that, at least your family can see that that is what we are doing. We are supporting them in their views as well. It is actually the whole gamut. It is not just the patient, it is everyone else.

Especially if we can do it well, we sometimes take away the guilt factor that the family might have had that they did not bring them in early enough. Nothing is going to change that, but sometimes it is good that we make decisions for them, that we do not ask them too much because some of them get guilty — ‘I cannot make that decision to go down the palliation and end-of-life treatment pathway’. Some people really find that difficult. So it is good when we can step in and guide them through it. It goes with the territory, but I have been working in intensive care for about 35 years, and it is one of the really good things we can do. It is actually how I would like to be.

**Ms FITZHERBERT** — I was thinking about what you were saying about intensive care. I am familiar with a couple of intensive care units — one I have visited and one I was a patient in, and I must say it was the most expensive hotel I have ever stayed in and probably the least comfortable. I was struck by how many difficult

conversations take place there because they need to, but it is a terrible environment in which to do it. If I think back to a very memorable night that I spent in intensive care, someone died in the bed next to mine and her family was there and it was enormously traumatic and relatively public, and I am interested in your views on whether there is any way around that. To me it seems to be an argument for earlier conversations, and that is not always possible, but on a practical level, how do you do that?

**Mr WHITE** — It is difficult. ICU is basically an open area with very little privacy. We do like to try and say that if the patient is conscious enough to be part of that decision, we actually need to do it with the patient.

**Ms FITZHERBERT** — Yes, exactly.

**Mr WHITE** — If they are not, then take the family just away and have the conversation, because it is also about how challenging it is for the medical staff as well to do it. Some people are more experienced and others are not experienced, or do struggle with it. It is about trying to be honest and forthright and have that conversation because that is the pressing point at the time. You need to be quite honest and open. The people in the other beds, we actually need to support them as well so that you actually provide something different for them, but a lot of people actually still tend to cope fairly well with it. It is harder for some people if they are in one bed and the other person looks fairly well and then suddenly drops dead from a heart attack or something. Then we have to try resuscitating them, and that can be more dramatic for them because they were just talking to that person. But when they can actually see the person is really struggling and is not doing well, then ears flap and everything else, and you can be hearing conversations going on and so on. So if the person is deteriorating but we are still having a conversation, people around would be able to track, through hearing, that they are in trouble.

Quite often, if the patient in the next bed is hearing, then they can also see what empathy we are giving and how truthful we are being, and it actually sometimes gives them reassurance that there is good care provided for them. It is not always bad. You can get a good side, but it is sometimes about a little bit of privacy if we can, but most of the time it is not open. But the conversation is the important bit at that time and then we support others as we can. I think the hardest thing for us is when — and because the wards are open — you get a drug-affected person going off their tree, and other patients around them feel quite nervous and quite threatened about that type of stuff. End-of-life treatments sometimes are a bit more comfortable for some people than others, but it is also cultural. Sometimes it is taboo to talk about it, so you do have to be aware of the perspective they are coming from as well as their family. The hardest thing is probably where the family do not want to tell the person they are dying. That is a really tough one, because we want to tell a person because it is their life.

**Ms FITZHERBERT** — Exactly. I have just one other question, which is slightly different. We have heard a lot of evidence on how it is good for people to have some sort of clarity about what their end-of-life plan is, or vague wishes, before they end up somewhere like intensive care. Do you have any sort of system to address that issue on arrival and discharge and, if so, what is it?

**Mr WHITE** — The difficulty with ICU is that we are geared to treatment. That actually needs to be done in the emergency or even before they get the ambulance and that stuff, so when we get involved it is actually pretty difficult.

**Ms FITZHERBERT** — It is not the best moment.

**Mr WHITE** — No, it is not, and it is difficult for the intensivist to then get hauled in. Here is this patient, and he does not know the person, and he has to say, ‘sorry, this is actually a terminal event which is going to happen’. I remember one time there was a problem out in the medical ward. I had just started work, I went out to see the patient because they called for help, and I did turn around, and I supported the nurses, and said, ‘This patient is dying’ to the registrar who was there. I then said, ‘Can you phone the consultant and just keep them informed?’. And the registrar started beating around the bush and the language was not good, so I just got on the phone to him and said, ‘A patient is dying. We actually need to make them comfortable, we will move them to a single room’ so in that case I provided the plan. The consultant was fully in agreement and said ‘Yes, no worries’. At that time they called the family, they came in, and they were comfortable and they could sit with the person for a while.

On the outgoing side, often from us, we send them to the ward. Because bed blockages do happen we do send some people home but not usually people with chronic health issues. They stay in hospital for a fair length of

time. They do have support services and people to provide them with support, but we do not really tend to get that involved with that side because the home team should be the ones who are driving it, not intensive care.

**Ms FITZHERBERT** — Sure, thank you.

**Mrs PEULICH** — Thank you very much for your evidence. We heard from an earlier witness who was talking about how ultimately personal autonomy will trump a range of other practices. Just in your experience, is there a stark or strong difference between the attitudes of white Anglo-Saxons and people from multicultural backgrounds or CALD backgrounds in relation to death and dying?

**Mr WHITE** — The biggest thing at present is that there is not a great difference because they do not face up to it here, regardless of what race or anything else. It is not part of their vocabulary, they do not have much in the way of discussions with their family or staff with them. As far as their engagement in treating people, it does not matter —, race or anything else. It is at an individual level. You might have some family members demanding all the treatment under the sun and sometimes you would have to say no, it is not appropriate, whether it is a Koori, an Italian or an Anglo-Saxon. It does not matter too much because the responses are still at the individual level.

**Mrs PEULICH** — So in your, did you say, 20 years' experience — —

**Mr WHITE** — I started nursing in 1979, that is when I started.

**Mrs PEULICH** — So over that period of time you have not seen — I see it — you have not seen a cultural difference, a cultural divide?

**Mr WHITE** — There are some cultural differences; some of the Kooris do not want their family member to know, because if they know they are going to give up the ghost and then just die so there can be some cultural things. But when we have a terminal event, what treatments they try to barter for or ask for sometimes does not matter because it is still at a family level.

**Mrs PEULICH** — And you do see it at the pointy end, the terminal end, the critical end that some of the discussions were relating to times preceding that. Having everyone on the same page, having these conversations — to me that is a very culturally laden concept.

I remember when my father was going through palliation, through palliative care, he was 63 years of age, a double degree graduate and did not want to talk about death and dying. I asked his treating oncologist whether palliative care would mean he that he would remain lucid until his death. He gave me a guarantee that he would. He did not, he was not, and we never had those conversations. I also asked the question whether palliative care would hasten death. After the treatment my father ultimately received, I am a great advocate of palliative care in having seen it practised then — yes, it was 15 years ago. Does it hasten death? In my view, it did. He received, first of all, tablets. When he was no longer able to swallow those, he received liquid. When he was no longer able to consume that, he was on an injection driver. The night before he died, a different nurse turned up to the one who had been liaising with the family. We were advised that if my father had not seen anyone and needed to say goodbye, tonight would be the night, because he would not live to the morning — and with that she gave him an extra two pumps. Three, as opposed to the usual one — and I have no complaints about that. My father did die a dignified death. I think that life is undignified, death is not.

But can we ever be on the same page? Can we ever have the safeguards?

**Mr WHITE** — No.

**Mrs PEULICH** — One thing that disturbed me — and I actually share that view, because I think it is human nature and I probably suffer from it as well — is that doctors and medical staff bring their own values to the situation. Some are clear advocates of a more robust regime of a form of euthanasia, and others are not. What safeguards are there that the views of the treating doctor or medical staff, ultimately if there were a more robust regime, would not prevail?

**Mr WHITE** — You are actually trusting a lot in the individuals surrounding it to respect the family. As a nurse, if the family ask you to do something which is unwarranted, you would not actually provide stuff which is unwarranted, even if it is extra doses. You can really see it is not going to work. You also have to be sure of

the disease process and what the person is facing, because you do not want them to just rock in and say, 'We do not want treatment, we do not want this'. But if the treatment is actually appropriate and if there is nothing to say there is a terminal event facing the person, then you should be obliged to treat if they have presented to hospital and are accepting treatment. If the doctor turned around and wanted to then do X, Y and Z, if it is not appropriate for that patient in my belief, I would not be party to it. If I felt that it was actually detrimental, I would escalate it through the chain of command up to my boss to say I have a problem with this occurring.

It is a bit hard because in ICU here we have an open unit. In other hospitals they have closed units. In that way it is actually good because we have the intensivists, the medicals and the surgeons coming in and everyone's judgement is a valid judgement. It is not one person dominating that conversation. You try to be a unified team. Sometimes you do not have that. As I said, it might be that the treating doctor brings their own values to it. There is one who does cause frustration occasionally who believes in the sanctity of life at all costs, and I think that is when we run into trouble because that is when we practice medicine probably inappropriately.

**Mrs PEULICH** — And how about the reverse? Or the inverse?

**Mr WHITE** — When you actually shorten things?

**Mrs PEULICH** — You know, you have a patient who is frail, old and consuming lots of resources. Is there no temptation somehow? Do you think that that is not possible to say, you know — —

**Mr WHITE** — There is always the possibility of the individual doing some silly things.

**Mrs PEULICH** — But it is not institutionalised?

**Mr WHITE** — It is not institutionalised. It is not. You see nurses who have been charged with murdering people, giving them too much insulin and stuff like that — that is a criminal act and is not part of normal treatment. If you see someone prescribing too much, again, there is normal dosage for things. Some of the drugs we give are quite different in other situations, like psychiatric drugs. I think I would blanch at the doses they use compared to what we would use in our setting to help their patients.

It is normal, the dosing. We have what is a standard practice across the therapies. You find the education process acute care nurses go through would be fairly similar. It is not identical, but it is fairly similar — you do anatomy, physiology and talk about similar drugs. You could almost put a blanket over Australia and even internationally with the medications — how much is normal, what you need to sedate patients, what you need to do and stuff. We use guardrails on infusion pumps and stuff which put in limits for how much you can prescribe of things, and it alarms. You cannot prevent things 100 per cent, but you can try to put safeguards in.

**Mrs PEULICH** — Thank you.

**The CHAIR** — Vin, thanks very much for your presentation and your preparedness to answer our questions. You will be provided with a transcript shortly.

**Mr WHITE** — Thanks.

**Witness withdrew.**