

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Traralgon — 9 September 2015

Members

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Witness

Ms Norma Kelly.

The CHAIR — I would now like to welcome Ms Norma Kelly, who is a nurse at the Sale hospital but who is appearing here today in a private capacity. Thank you very much, Ms Kelly, for being here with us today. Before we start I will just 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 a proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website. We have allowed half an hour for our time today, so I invite you, Ms Kelly, to make some opening remarks and thereafter the committee will have questions. Thank you very much for joining us today.

Ms KELLY — Thank you very much. Yes, I work at Sale hospital. I am a nurse in the surgical ward. I have got six grandchildren, three up there and three in Melbourne.

I have initiated lots of conversations very recently about this issue, and I can honestly say that I have had nothing but support, which is very interesting because everybody who gives me support has their own story. They have got their own experience with a friend or a partner or a neighbour or some member of their family. They all agree there is a need for something better.

What we are after is like an insurance policy. No-one really hopes that they are going to need it, but we do not know what is going to happen down the track. Probably 90 per cent of the people who are going to support this are going to live to be 90 and die in their sleep — marvellous.

The point needs to be made that it is very much a choice. People need to know that this is not something that is going to happen to everybody without a lot of consultation, that everybody has to have a choice, and if people who oppose it realise this — that it is an absolute choice — then it should not have so much opposition. Not that I have found any opposition, but one person suggested that there would be opposition because people would become frightened that it is not going to be their choice.

There is a lot of fear out there. People are frightened. They are frightened of being in this dreadful situation where they are going to be in a lot of pain, because they have seen so many people go through so much treatment; and the end drags on and on and on, and they are just suffering. They have just got a lot of pain. A lot of people do not want to stay at home at the end. They prefer and choose to go into hospital to die, because they imagine that it is going to be so stressful for their relatives and their loved ones and the people caring for them if they die at home. They have got this dreadful fear that: my gosh, what will happen to them when I die and I am not there? So they choose to come into hospital.

Sometimes they are not really right at the end, as everyone believes they are. It is only a few weeks since one lady came into hospital, a very old lady who had had mega amounts of treatment because she was advised that this was very near the end, she only had a few days left. She lived for nearly four weeks in awful pain, in awful suffering, and just wanting to go. She said, 'I can't even hear'. Right to die in 5 minutes, sort of thing. She said, 'Here I am', and she ended up like a limp little rag doll in the bed. I am sorry, but sometimes it does not matter how much medication you give people, when you turn them over — and you must turn people, you must move them in the bed, otherwise they get dreadful pressure sores — they do respond and they do become kind of conscious for that little while. I have people looking right into my face and begging me, 'Why am I still here? Please can't you do something'. It is not a very good thing to have happen to you.

It is all very fine to be told, 'They're not your family, they're not your loved ones', but very often you have looked after this patient off and on for the last five years because they have been sick, so you kind of get to know them. You get familiar with them, you get to know their family quite well — and this goes on and on and on, and sometimes the pain management does not really work all that well.

Another lady — who was not an old lady; she was in her 60s — had stayed at home, lived on her own, had no family and was going to stay home. Palliative care went there and she could not even get out of bed, so they said, 'You have to go to the hospital; we can't walk away and leave you here'. She agreed; she said, 'Yes, all right. I will'. That went on and on, too. Because — I do not know — she was obviously a strong lady and her heart was strong, we could not get rid of her pain. Out in the corridor we could hear her groaning and saying, 'Oh, pain'. It was just awful.

Which brings about another issue. Junior doctors are not in a very good position about this. They are very hesitant to order large amounts of morphine or haloperidol or any of these drugs that are really going to knock the patient out, which is what we really need. They are just fearful of it. The patient keeps what we call breaking through with extra pain, and we cannot get it under control. At 11 o'clock at night I am sitting there with a lady looking at me, begging me to end it — 'Please, can't you do something? I know you can't, but can somebody?'. That is really not good enough.

I know I am speaking for myself, but I have got lots of nurses who get really very stressed about this. I know I am an older nurse, and if they are going to beg somebody to kill them, then I am going to be it. They are not going to beg some young 20-year-old girl to do something like that. I wish I had a dollar for every time I have said to a patient, not just dying patients, all sorts of patients who have come to me and when I go around to tend to them, they will say, 'This happened last night. I've got this dreadful pain', somewhere or other or, 'My head feels as if it is splitting or something', and I will give them a general reassurance. Then I will say to them, 'You need to tell your doctor that when the doctor comes around'. 'Oh, I can't tell my doctor that'. Hello?

Also there was another young woman I was looking after the other day. She had had a medium operation. She was going to go home, she was going to die, she was going to fit and she has three adult children at home. She started telling me about when her husband died. She was 32, he was 36 and she looked after him at home, with three little kids. That went on and on and on. She said, 'How I ever got through it, I don't know. I was doling out morphine to him. He was begging me, "Get someone! Do something. Go find something"'. And then he was saying, 'I've got three little kids; they're watching me die. This is dreadful. Go and do something. Just get it over with'. She said the trauma of that.

I might add that she told me that this day he was so bad, and someone was looking after her children away from home, that she put a little bit more morphine in his dose and she told him. When she went to give it to him, she said, 'I've put more morphine in that', then she got terrified and went for walk and came back and then got on with her housework. When she went in a few hours later, he had died, which was probably best. Then the fear set in. She said she put in the worst month of her life. She was absolutely terrified someone would be able to tell that she had slipped him a little bit more morphine in the dose. She said she had to have someone look after her kids. She said she nearly went off her face because she thought, 'I'll end up in jail. Their father's died, and now there's going to be no-one to look after them'. Then she started to realise, 'Don't be stupid. The little bit of morphine that you put in didn't make any difference, anyway. There's no way anyone could find it', but she said she has lived with that ever since. Her brain tells her, 'No, I didn't really do it. I didn't make any difference', but what she does say is, 'The look of peace that came over his face,' when she told him that. She said, 'I'll never forget that. All the terror went out of his face, and he just was looking so peaceful'.

These are all the sorts of stories we get told over and over. I have made some notes, but now I cannot read them. They really do not want to tell the doctor all these nitty-gritty things, though, 'Oh, no! I can't tell my doctor that', but they will tell us — and me. If I am talking to some person who is in a pretty dire situation and it is 5 to 11 and I am supposed to be off, I find it very difficult to just walk away from a patient just because it is my time off. Because they have plucked up the courage to be open and honest and tell someone about it, I find myself reasonably often sitting there until late at night, letting someone tell me some deep, dark secrets or some secret wishes. This is not out in the community, although — like everybody else, just speaking to people in the community — everyone has got a story. Everyone will tell you about the story. It is the drag at the end that seems to be so horrendous. People are in pain and there are people you just cannot get out of pain. That is where I am coming from.

The CHAIR — Ms Kelly, thank you very much for giving your position and drawing on your experiences. The committee appreciates it.

Ms PATTEN — Thank you, Ms Kelly. You sound like a wonderful nurse, the way you care. I really appreciate what you have talked about. If we were to look at helping these people at end of life, as they are asking for, we need to get in some sort of regulations. As you know, people worry and, as you said, it is going to happen to everyone. Have you got any thoughts from your position as a nurse what sort of regulations and controls we could put in place so people would feel safe and protected?

Ms KELLY — People are very frightened. They are frightened that at the end of their life they are going to get into this situation and be in pain, and no-one is going to be able to do anything for them.

Ms PATTEN — What sort of rules should we have there?

Ms KELLY — Maybe while people are still, I do not know, 50, 60 or 70 years old, and they are not terminally ill, they are not in a drastic situation, they could then make a decree in their will or somewhere like that that they would have no objection to having euthanasia should they get into a situation — for example, if they have had a stroke and they are on a respirator and then they are in a ward and they are not going to be able to do anything and they cannot talk. Do they want to live like that?

Then they get pneumonia, because they cannot move much — ‘Do you want to be resuscitated?’. It is not a very good time to ask someone, ‘Do you want to be resuscitated?’, when all this has happened and they cannot think straight and they cannot move their arms and whatever. So then you could have that already documented, that this person has no objection, so then maybe a panel of people who have looked after this lady could make some sort of a decision on that. Also if they have cancer and they have got terminally ill, they know at the back of their mind that they have got this in place — ‘Well, it’s not too bad just yet’, but in a little while when they’re going to need it, they know that they have got it in place.

Ms PATTEN — And you would have a panel?

Ms KELLY — Yes. Or a little closer to the time they could then have it brought up again — ‘You know you’ve got this in place. Are you still prepared to do that?’, and just — —

Ms PATTEN — Give them that choice again?

Ms KELLY — Give them the choice again, yes.

Ms PATTEN — I was interested when you mentioned that the young doctors are very fearful of providing what you would see as appropriate pain relief. What are they fearful of?

Ms KELLY — I am not quite sure, but I can cite a little incident that really made that very plain to me. I received a patient from casualty. They said, ‘Quick, we’re getting this lady up to you’ and when she came I could see she was not going to live very long. She had really very bad cardiac failure, and she had been in an out in the last six months a lot of times, and I knew she was right at the end.

So I very quickly got the medical registrar there. I said, ‘We don’t have a blue form’, a resuscitation plan, and I said, ‘Can you get here and do it quick, because this lady is on the way out’. So he came and there was the patient, who was, for the state her health was in, quite rational, very vocal and able to talk. She was a bit short of breath, but she was well able to get her message across. There was her daughter, who was probably in her 60s, and there was the doctor and myself. When he came up, he said, ‘Now, we need to write out a form to say what we’ — a plan. He said, ‘Now, in the event that you should, that you should’, and he could not even say it. I said, ‘So, Mrs Jones, in the event that you actually die, would you like us to resuscitate you?’. ‘Oh, no’, she said, ‘I don’t want any resuscitation’. I said, ‘We will treat you fully and care for you fully, but in the event that you do die, you do not want any resuscitation?’. ‘Oh, no’, she said, ‘and I’m not going around to that coronary care place, either. I’ve been in there and I’m not going there. And if I die, don’t touch me, just don’t touch me. I don’t want anything. I’ve been so sick, I don’t want to just keep going like this. Just leave me here, don’t touch me’.

Then he said, ‘Oh, well, I’ll just listen to your back’, and rah, rah, rah. The next minute, her eyes rolled back and I thought, goodbye, Mrs Jones, and she died right there and then. The daughter was there, and the daughter was just sort of looking at her and looking at me. I put my arm around the daughter, and she said, ‘Has she, has she?’ and I said, ‘Yes, she has died’. She sort of stood there for a couple of minutes and held her hand, and then she got out from behind the curtain where we were.

The doctor said, ‘Quick, lie down. Have we got IV access? Quick, ring the code’, and I said, ‘We just went through all that with this lady. She wants nothing, she wants to be left’. ‘Yes, but we can’t not make some effort’, and I said, ‘Yes, we can. This lady has just told us what she wants done. If you’re going to attack this lady and start pumping on her chest, is that not assault? We don’t have permission to do that’. He was almost going to start, and I said, ‘Don’t touch her. You’ll have me to deal with. Why bother getting a blue form, if we’re going to do that to this lady who’s just died quite peacefully? Nature’s said that this is enough’. He was a bit beside himself. I said, ‘Look, it’s fine. That’s what we are here for. Now, the family are all out there. Who I

have to treat now are the family. They expected this lady to die. Now I have to take care of them. I have to go out and reassure them'. That is what we do when relatives are there.

I got home that afternoon and I thought, I feel really sorry for that young doctor. He is only a registrar. I mean, he might have been 30, but he is still a child. They are so young, these doctors, and I felt sorry for him. I thought, I should have gone, when I knocked off work, and found him and just given him some reassurance that what he did was okay, that he did not have to put up some act of trying to save this lady. That made it very clear to me that this young man was in a dreadful position.

The CHAIR — Ms Kelly, do you think that in medical school the doctors receive enough education about palliative care and end-of-life issues?

Ms KELLY — No, I do not. I cannot really say much about palliative care because I have not done palliative care in the community. But no, I do not think they have done enough about end-of-life crises and about allowing patients to cease having treatment. They kind of assume that the patient is going to go on having treatment as long as they are going to be prepared to give it.

A very dear, dear friend of mine who had cancer, was down here for many years, went to Queensland because it was too cold, could not stand it down here. He was in touch with me two or three times a week by phone and he kept saying, 'I want this all to stop. I just want to die. What can I do?'. Then he rang me desperately one day and he said, 'Look, they're planning all this treatment', and I said, 'Look, just say to the doctor, "I don't want to have any more treatment"'. 'Oh, I can't say that. I can't say that to a doctor'. I said, 'Well, you need to. Get a piece of paper, write down: I really appreciate all you've done for me, but I've made a decision after a lot of extensive thought about it, and I don't want any more treatment'. I said, 'Write that down, stand in front of a mirror and keep saying it, over and over again, until you can go in and say that to your doctor'. 'All right'. He rang me up as soon as he got home from that appointment and he said, 'Guess what? I said that to the doctor. I had it all practised up and I said it to him, and do you know what he said?' 'Oh, thank goodness for that. I didn't know where to turn to next'. That really happened; that is what he said.

There is something missing somewhere and we have to sort of fill in the gaps, instead of assuming that the patient is going to go on and on and on having this treatment, which makes them so ill. I mean, some of them have a treatment and then they have to come into hospital for a week to get over the treatment. It is really, really tremendous; it is awful stuff.

Do the GPs, the oncologists — particularly the oncologists — give a patient an out? Are they trained to allow the patient some sort of choice about further treatment and are they honest that the treatment is not going to work? I do not know, but from where I sit, it is not very good and it is traumatising to the nurses, apart from anything else. I appreciate the chance to come in today and speak.

The CHAIR — Thanks very much, Ms Kelly, for your evidence today. The committee very much appreciates it.

Witness withdrew.