TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Geelong — 29 July 2015

Members

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Witnesses

Mr Mark Arnold, Nurse Manager, Inpatient Rehabilitation Centre, and
Mr Christopher McCormick, Nurse Unit Manager, Barwon Health.

Necessary corrections to be notified to executive officer of committee

The CHAIR — I welcome Mark Arnold, the inpatient rehabilitation centre nurse manager, and Christopher McCormick, the nurse unit manager, at Barwon Health, and thank them for being here this morning. It is very much appreciated. I caution you both 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's standing orders. Therefore you are protected against any action in relation to what you may say here today. However, any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded and you will be provided with a proof version of the transcript in the next week or so and transcripts will ultimately be made public on the committee's website. I invite you to make your opening statements and the committee will have questions thereafter.

Visual presentation.

Mr McCORMICK — I was just thinking before this hearing that there are so many end-of-life choices and wondering what would I pick to present today. I think, coming from the palliative care unit, the choice of a patient to want to die in the palliative care unit and be looked after in the terminal phase is something that is quite significant for us to be thinking about so I have just got a PowerPoint presentation that is going to talk around these issues.

The palliative care unit on the north wing forms part of the inpatient rehabilitation centre. It consists of 16 inpatient beds providing specialist palliative care for patients with life-limiting illnesses and complex needs. Symptom management, end-of-life care and discharge planning are the main services we provide here.

Last financial year, 48.9 per cent of community palliative care patients — we see those patients too — had their wishes for their preferred end-of-life care setting fulfilled; the most common being at home, followed by the palliative care unit. Of those patients who requested that they die in the palliative care unit, 63 per cent had their wishes fulfilled. The remaining died in hospital, in residential care and at home. For that year also throughout Barwon Health and across our services, 909 inpatients died. Only 231 of them died here in the palliative care unit.

The waiting list is something that could be a contributing factor to the low numbers there. With an increase in service demand we are seeing lists extending to 1.9 days as an average waiting time for patients requesting to come to the palliative care unit. Almost a quarter of those patients waited longer than the average time and the longest waiting time was 13 days. The total number of days patients spent waiting during this period was 533. The limitation of the data, however, is that it does not include the patients who never made it here at all. The data only includes the patients who actually came here. Patients who did not come here died whilst waiting, became too sick to transfer or transferred elsewhere because beds were not available.

Other factors that influence access to the palliative care unit include patients who stay longer than expected. Of those patients there is generally a population with progressive slow illnesses and increased disability. Those illnesses are glioblastoma or brain tumour, spinal cord compression resulting from cancers around the spine — mainly prostate cancer — motor neuron disease and lung cancer. They make up 56 per cent of the patients who stay longer in the palliative care unit.

When it comes to the reasons why they stay longer, we are thinking that age may be a factor. The average age of people we are seeing with these combined diseases is 64 years. Other reasons are their prognosis, the issues surrounding the implications of permanent residential care for this population and other discharge planning concerns.

With an increase of 20 per cent projected for the population in our region by 2026 it can be expected that service demand will increase, so the consideration for us would be looking at how we can ensure timely access to our inpatient service and how we can better fulfil that wish to die and to be cared for in the palliative care unit at the end stage of life.

The CHAIR — Thank you very much for your presentation. Perhaps I could ask the first question. You talked about some of the demand pressures that you are seeing: the cumulative wait time for people seeking to access your services here and the 20 per cent increase in population by 2026. Can you talk us through how you manage those demand pressures and can you perhaps talk a little bit about some of the opportunities the new unit may present once that is open and operational?

Mr McCORMICK — I suppose I could start with what we are working on now — our current resource. In regard to the patients we are talking about who stay a long time, the 40 days-plus patients, at the moment we are looking to create alternative placements for them. The project is looking at residential care here at McKellar to support these patients with input from the palliative care team also. It would be almost like having palliative care, but not specialist palliative care because they are more disabled than medically unwell. If they were unstable and medically unwell they would be with us, but as they become stable and it is presumed they are going to live longer than the average length of stay, it would be worthwhile to transfer them to residential care but still provide the same service to a lesser extent than currently.

Mr ARNOLD — There are probably two factors in this. There are the people who are under 65 and there is quite a complex process to get them into an aged-care bed because, as we know, aged care is funded through the commonwealth funding system so we have to go through the younger persons. Also you are dealing with people whom we know have a shorter prognosis and are transitioning from home or from a palliative care unit into residential care. People are dealing with the grief of the move and the grief of someone dying while at the same time trying to balance that with the thought that 'I'm putting mum, dad, my husband, my wife, my brother or my sister into a residential aged-care facility'. That makes the whole complexity of the transition to care even more complicated.

As Chris was saying, a lot of the people with the glioblastomas are also younger people and so it is about matching the resources of the residential aged-care people with providing care for these people, so it does add another level of complexity into a transition.

Mr McCORMICK — They kind of sit in between the needs for resource in a specialist palliative care unit and residential care. They may not need everything a specialist palliative care unit provides, but they need more than what is provided in current residential care and we have to fit that gap.

Ms SPRINGLE — You talked about the people who could not get into this facility and so they either did not go anywhere or they found somewhere else to go. Where would that be? What are the other options?

Mr McCORMICK — They include patients in the acute hospitals and in the community, so I would say that those patients who were in the community either stayed at home or went to the emergency department at the University Hospital Geelong.

Mr ARNOLD — Obviously being on a different site if it becomes known that the acute cancer of this person is progressing and they are going to die quite quickly, moving someone at that stage is not good. Unfortunately for some people the family will try to care for them at the home, which is great; we want that if that is preferred. But sometimes there will be an emergency situation and the family is no longer able to care for them at home. If we do not have a bed in the PCU, the default position unfortunately becomes an emergency department. You are sending someone with a known terminal illness, who is probably in their last stages of dying, into a busy emergency department and, as we all know, that is not ideal for anyone. It is not ideal for the emergency department and it is less than ideal for the patient and their carers.

Ms FITZHERBERT — I was interested in what you were saying earlier about younger people who come here, younger than the 64-year age you mentioned. If they did not come here — and you mentioned the problems; it is actually an aged-care funding bucket here and the difficulty in transferring someone into that — where would they go?

Mr ARNOLD — That is the question that we are all grappling with at the moment. Obviously we can only talk about our area. There are no nursing homes that specialise in the care of younger people. I do not know what resources are available in Melbourne or if metropolitan places have service specialisation there. This is a growing area that as a health system, as a government, we are going to have to look at, because we have people with disabilities, we have people with life-threatening illnesses, and some of these people will be young. As a system, how do we care for them? I am not aware of any great answers to that yet. It is not a decision in the PCU that Chris and the team will make lightly. It is a decision that involves a lot of consultation with families, with the patient or with the client themselves, because, as I said, these people are dying, and also we are talking about a transition to another facility that is not really suited for them either. It is a very hard process, is it not Chris?

Mr McCORMICK — All other options are usually exhausted before we go down that track, so that kind of extends their stay even more before the decision is even made to move to residential care because of all the emotions around it.

Mr ARNOLD — We will see what home supports can be provided, we will exhaust all the home supports. We will do everything possible, but at the end it is a very hard process for all involved, and certainly for the staff involved too because they know they work in a complex area.

Ms PATTEN — Thank you. We recently heard from the Grattan Institute. Their *Dying Well* report says that 70 per cent of Australians would like to die at home and yet only 14 per cent do. In your opinion, do you think that is realistic? I appreciate you are talking about younger people, but do you think it would ever be realistic that 70 per cent of Australians could die at home as they wish?

Mr McCORMICK — When I speak to patients and they are asking to die at home, generally what it seems to be about, after unpacking it and having some consultation is: ‘I do not want to be here and I do not want to be sick. To me home means I am okay’. But a lot of the time when I was working in the community, people would not feel safe at home. They would be waiting for the next pain crisis or waiting for the next time they are short of breath and needing oxygen. They did not feel safe, so the quality was not always there. But the desire to go home and to be cared for at home is not often exactly what they mean. It is often that ‘I do not want to be here, I do not want to be in this situation, I do not want to be sick’.

Mr ARNOLD — Certainly to die at home, the impact on the carers and the ability of the carers is crucial.

Mr McCORMICK — Having a carer is crucial.

Mr ARNOLD — Having a carer is crucial. As we know, as a society we are not going into those extended families anymore. There are more homeless people and other things, so the ability even to die at home can be quite dependent on the ability of the carer. Even with the best services in the world there needs to be a carer. If that carer is able to handle that burden, it is good, but it can be quite difficult on carers at times.

Mr McCORMICK — For the population we see, it is a complex set of issues.

Ms SYMES — Thank you very much for your presentation. Just a question about end-of-life pain relief, and you would be familiar with the principle of double effect. We have heard evidence of people promoting changes to the legislation so that doctors and nurses who administer pain relief that may result in hastening death are protected under the law. I am just wondering in a practical sense whether the current legislation is something you feel hamstrung with? Is there anything in a day-to-day practice or is it just something that is separate to your operation? Is it a factor for you and, if so, should there be changes?

Mr McCORMICK — I do not think it is a factor for us really. There is a reason why we would give pain relief, and the reason is pain. If there is no reason there, if it is the patient asking for it, it would be, ‘Why are you asking for it? Are you distressed? Are there any other problems?’. That would lead to possibly other medications, maybe an anti-anxiety medication or something to make whatever is happening or upsetting that patient go away for that period of time, not permanently. If it is family requesting medications for pain, generally we would talk about how the patient is looking. We would probably give pain relief in that instance, and then in measuring later if that has changed, determining what is going on.

Just reflecting back, probably a couple of months ago we had a patient who was in the dying phase. They were unconscious and very comfortable from what nurses were observing. Adequate pain relief was there, all the medications were, but the family became distressed because the patient’s breathing had changed — it became rapid. They thought he was in pain. We gave medications for pain, and generally that would settle breathing as well — the same kinds of medications. So after half an hour of waiting for it to work it was perceived not to have worked. But quite often too during that phase of life breathing will change and the patient can be completely relaxed. Just looking at the patient you could see they had soft lines in their face, they just looked pleasantly asleep. But that breathing had become quite shallow, so it was quicker — it was an automatic response. What we were doing with the family was supporting them to understand what was actually happening, that this perception of suffering is not really there, that it is an automatic process and that that medication did not change anything. It did the other time they had it, but at that stage this is not something we can change. We try to show that understanding to the family, but we would not just say, ‘You are not having anything’, there is somewhere in-between.

Mr ARNOLD — The unit will work with the families and go through the dying process with the families and explain that dying process. Certainly medication would never be withheld if there were symptoms. They will spend a lot of time working with the families explaining that process. You are right, sometimes — as Chris was alluding to — what is perceived as pain is actually anxiety or restlessness, and at that stage sometimes other medication is more appropriate and that can bring pain relief.

Mr McCORMICK — Just to add to that as well, I think having an understanding of the medications too is the reason why I do not think it is relevant. The amount of medications that we give are quite huge at times compared to general nursing, but still not enough to end somebody’s life.

Ms PATTEN — I have one question, and I am not sure you can answer it.

Mr ARNOLD — Thank you.

Ms PATTEN — Feel free not to. In going through all the submissions and in the debate that we are seeing around this inquiry and end-of-life choices, obviously physician-assisted suicide or voluntary euthanasia is commonly raised. Do you think having that within the toolbox would provide any comfort to your patients who are seriously ill at the end of life?

Mr McCORMICK — To palliative care patients?

Ms PATTEN — Yes.

Mr McCORMICK — This is a personal opinion I see it as being not opposed to palliative care but quite separate from palliative care. I think those requests are when palliative care is not there or is not adequate. When there is real suffering, whether it be for symptoms, I think it is hard to know when to chime in with this and when to pull back a bit.

Mr ARNOLD — You are right. They are two separate issues.

Mr McCORMICK — What I believe is if you have a problem and you are having symptoms, whether they be physical or emotional, palliative care can help with that, be it anxiety, be it pain. Whatever suffering that is, we can help on that time-limited part, not offer a permanent solution to it. It happens anyway.

Ms PATTEN — Yes, that is what we are hearing.

Ms FITZHERBERT — I know that where you work there is a special process guiding the choices that people have, and I assume most people have gone through that process by the time they reach you, but in general terms, thinking of the broader community, do you think people are well informed about the end-of-life choices they have?

Mr McCORMICK — No, not really. I do not know what all the choices are, and I think offering choices without knowing what is available is a bit difficult too. Jill Mann was here before doing an advance care plan talk. When I see doctors just assessing patients — it is not refusal of treatment, what is it called, the alert sheet?

Mr ARNOLD — Limitations of treatment.

Mr McCORMICK — Limitations of treatment. Doctors ask them, ‘Do you want CPR?’. Why would you ask somebody who is dying if they want CPR when it would not be offered, really, because it would be termed medically futile? Why do we not offer things that people can actually have and that we can give them instead of just having this open list, ‘What would you like at end of life?’.

‘I would like to live on the moon’. We need to have some guidelines. We need to know what resources we can provide so we can say, ‘Would you like this at end of life, or would you not like this?’, a bit like the statement of choices. The most important thing for people to document or even have their wishes known is how they would like to be cared for when they cannot let us know. That is the biggest issue that we see.

The CHAIR — Mr McCormick and Mr Arnold, thank you both very much for your presentation and your evidence this morning. It has been most insightful from that practical perspective. Thank you very much.

Mr McCORMICK — Thank you.

Mr ARNOLD — Thank you.

Witnesses withdrew.