

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Warrnambool — 30 July 2015

Members

Mr Edward O’Donohue — Chair

Ms Fiona Patten

Mr Daniel Mulino

Ms Nina Springle

Staff

Secretary: Ms Lilian Topic

Research assistants: Ms Annemarie Burt and Ms Kim Martinow

Witnesses

Associate Professor Tim Baker, Director, Centre for Rural Emergency Medicine.

**Necessary corrections to be notified to
executive officer of committee**

The CHAIR — I declare open again the Legislative Council’s legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. The committee welcomes Associate Professor Tim Baker, director of the Centre for Rural Emergency Medicine. Thank you very much for joining us today for these deliberations. The committee has allowed half an hour for your presentation. Shortly we will invite you to make some opening remarks, and then after we will ask questions. Before we do, 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’s standing orders; therefore you are protected against any action for what you say here today, but any comments made outside the hearing will not be 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. Thanks again for joining us, and we look forward to hearing what you have to say.

Assoc. Prof. BAKER — Good afternoon. My name is Tim Baker. I am an emergency physician in south-west Victoria and director of Deakin University’s Centre for Rural Emergency Medicine, which is a partnership between Deakin University, the department of health in Victoria, Alcoa Australia, South West Healthcare and Portland District Health. I work at the emergency department in Warrnambool as well as at several very small emergency departments in this region, which in Victoria are called urgent care centres. I want to talk about the end-of-life decisions that are made in these urgent care centres.

There are 45 urgent care centres in Victoria compared to about 39 officially designated larger emergency departments. Together they see approximately 140 000 patients each year, which is almost 10 per cent of all emergency presentations in Victoria. As they see a generally similar spectrum of patient problems to the designated emergency departments and they see many elderly people, it is likely they see approximately 10 per cent of patients who require end-of-life decisions in an emergency care facility.

I do not think anyone plans to die in an emergency department or in an urgent care centre, but people with excellent palliative care support and plans can sometimes be brought in when they become too sick to die at home, which sounds wrong, but sometimes a person’s symptoms, especially pain, become too difficult to control at home. They come to hospital to regain control of the symptoms, and sometimes they are admitted to hospital for the final days of their illness. This is something that many small rural hospitals do very well. Palliative care is a large part of what they provide the community, and people get to die in their home town near family and friends.

Regional palliative care services provide education support in difficult cases. A patient may even die in the hospital they were born in. Other people face imminent death in urgent care centres because of sudden or unexpected illness. This can happen to people of any age. The treatment goal for these patients is often clear, too. They need to be stabilised and transported with the help of the statewide retrieval service to larger hospitals for intensive care and, hopefully, life-saving care. For some patients though, transport to a bigger hospital is not what they want at all. For elderly patients or patients with chronic disease the chance of surviving, even with intensive care at a big hospital or even surviving the flight to the big hospital, is not high. The goal of care could be providing comfort and alleviation of symptoms, and I am sure the committee has heard this type of suggestion before.

Unfortunately there are a few peculiarities about urgent care centres that make end-of-life decision-making more difficult and result in patients being unnecessarily transported to larger centres. Moving unstable patients often requires them to be placed in an induced coma with a tube down their throat and on a ventilator to make the journey safely. Then they die in a large impersonal hospital away from their family and friends, and their last words are usually to the retrieval team reminding them, ‘Don’t forget I’ve got false teeth’, rather than to their family reminding them not to forget them.

It is harder to work out exactly what is going on with a patient in an urgent care centre. They lack CT scanners and sometimes even radiology and pathology testing, so it makes it harder to be certain that the patient really is dying. At larger hospitals a CT scan can show that a patient has a big bleed in the brain, that the rest of the brain is being squashed and that there is no hope that that patient will survive. In an urgent care centre there is no CT scan, and the diagnosis must be based on the patient being unconscious with perhaps less movement on one side and not much reaction from their pupils to light.

Urgent care staff might have less recent experience with critical care and critical illness. They might only see a shock after a major heart attack or severe pneumonia once every few years. They can lack confidence that they really know exactly what the diagnosis is. They also lack the confidence they can provide a good estimate of how likely it is a patient will survive an illness or the injury they have. This makes end-of-life discussions difficult for rural doctors, even when their palliative care skills in less urgent settings are really quite good.

The nursing staff may lack this experience too, and it is often the nursing staff who are left to re-explain what it is going on after the doctor has left. Patients and their families might have less confidence in their clinical staff. They trust and value their general practitioner highly, but they know that critical care is not really their GP's area of expertise. They want to be absolutely sure of their facts that they are basing their decision on.

There is a natural bias to erring on the side of treatment if they are uncertain if the condition is unsurvivable. This lack of confidence can be greatest when an elderly patient's children have moved to a capital city. Again, there is perhaps an unfounded belief that rural doctors are less capable than their urban counterparts.

It is often left to the critical care experts working for the statewide retrieval services to assist in these discussions. These experts are experienced in determining how likely a patient — a person of a certain age with a certain set of pre-existing medical conditions, the likely diagnosis and perhaps the current pulse and blood pressure — is likely to survive. They know which problems are the most dangerous. For example, they know that a person with a low blood pressure due to a big infection is 50 times more likely to die from that illness than if they are operated on for cardiac surgery.

They also know that if they transport the patient no intensive care unit will want to accept them and that the intensive care unit will probably want to withdraw intensive life support treatments soon after the patient arrives and let the patient die anyway.

These discussions are difficult to have at a distance though. Videoconferences set up quickly, often in the middle of the night, between retrieval services, local doctors, patients and carers can certainly help, and this occurring in Victoria now, but not every urgent care centre has access to videoconferencing and the resources of the retrieval services are limited, making the prolonged discussions that are required in these situations difficult.

What would improve the situation? What would make it easier for rural people to have their end-of-life wishes met? I would like to mention two things. One the committee must surely have heard before is a need to encourage more people to discuss their end-of-life wishes with their family, friends and doctors. They may very well be certain that they do not want heroic end-of-life measures and they want to die in their own town, but they might be too sick to tell anyone when the time comes. Advance care directives certainly make these decisions easier.

Secondly, the retrieval services, and in Victoria that is Adult Retrieval Victoria, need some more resources to perform their work in this area at present, to enhance the skills of these critical care positions and end-of-life discussions and perhaps to investigate the best ways these discussions can be made at a distance would be helpful. Confirmation from the department of health that end-of-life decision-making is part of their core business would help invent these processes, and an education package that Adult Retrieval Victoria could provide to rural doctors along the lines of their recently released trauma education package for rural doctors would help rural doctors be more confident in this area too.

The CHAIR — Thank you very much for that presentation and that information. I would be interested if you could give me a bit more detail about the fact that more people are having discussions about end-of-life issues and having advance care directives. We have heard evidence from other witnesses that there should be certain triggers that mandate these discussions at a particular age or a particular health situation that may arise. Have you got any views on that? Obviously there is work going on to encourage these discussions and to encourage increased community awareness, but do you believe that we need to have, through the system, some sort of mandating of referral points when people come into the health-care system at a certain age or as a result of a certain trigger?

Assoc. Prof. BAKER — I think in general advance care directives are really helpful for us; however, they do not stop us still having to have these discussions, because the situations in the advance care directives are not the specific situations that the patient is facing at the time. But to have that as a background and a starting point is incredibly useful. I think it seems to be close to mandated, but I am not sure how it works for people in

aged-care facilities to have an advance care plan. Where once almost no-one from an aged-care facility had an advance care plan, even when they were incredibly ill, now I find the majority of people do, and perhaps even all people do. That certainly helps. It would be very difficult to mandate members of the community to have this discussion because they need to engage in the discussion, not just have the discussion. I imagine that already in perhaps the general practice quality standard there is something suggesting that all patients have end-of-life discussions. It may be, say, that kind of thing possibly would work, but that is getting a little out of my experience.

Ms PATTEN — Thank you Professor. In a lot of my questioning my first question is, ‘How do we fix this?’, and I think you have made some really great recommendations. I hope that we will get to speak to the retrieval services during this inquiry to see what their suggestions are as well. I would like to turn to something slightly different. We have received close on 500 submissions to this inquiry, which shows the real community engagement in talking about death, which I think from everything we are hearing is nothing but a good thing. Many people are talking about voluntary euthanasia and physician-assisted dying, and from looking at models such as the Northern Territory one, where it was very specific about the processes and the legislation, do you think that physician-assisted dying is something that could work in a regional setting?

Assoc. Prof. BAKER — I think that is really out of my area. I do not have long-term contact with patients like a general practitioner will. I see them when they are really already incredibly unwell, and the decision-making that I am involved in always centres around whether we should provide curative care or attempt to, or palliative care. I have never been in the situation of talking about voluntary euthanasia; it is just not the area that I am involved in.

Ms PATTEN — Thank you. Just following up also on what you were saying about the Trak retrieval system, is that something we could see in some of that advance planning? Could we have people saying, ‘And I don’t want to be airlifted to Melbourne’; that would be something specific, because we talk about ‘don’t resuscitate, don’t provide this, this and this’. Maybe we could be specific about ‘don’t put me in an emergency copter up to Melbourne’.

Assoc. Prof. BAKER — Yes, I had not thought about that, but that is not a bad idea. There is a small number of things that they put, such as not being ventilated, and for a country hospital not being aeromedically retrieved would be one. But again the situations are all individual and unique, and you always need to have some discussion around them because a person might not want to be transported for one illness, but, say, if they had an allergic reaction to their antibiotics and their chance of survival with that illness is actually quite high, they might want to be. I think it would not be a bad thing to put on a form for rural people about what they would like, but it would still have to be interpreted in line with the actual thing that is going on.

Ms PATTEN — It could be part of the conversation.

Assoc. Prof. BAKER — It makes an excellent start point for what we are talking about because you know where people are coming from, and it is a great comfort to family members, who in this situation are almost always the decision-makers because the patient is too unwell to make the decision, so if they can see what the patient — often a parent — has written — —

Mr MULINO — One of the issues that has been raised by a number of people and in a number of different contexts is the fact that medical practitioners who do not necessarily work in palliative care day-to-day may need more training in or understanding of some of those issues. Particularly, for example, if we want GPs to be engaged in some of these earlier discussions, it may be that some of them need more of an understanding of some of the issues that are going to arise. What are some practical steps that you think might be useful in tooling up the people in the medical profession beyond those who work day-to-day in palliative care?

Assoc. Prof. BAKER — Talking specifically about emergency physicians, we are often involved in these discussions, and so I think have quite a lot of experience in these matters, although not being directly involved in palliative care. We face the problem that we tend to want to focus on resuscitations and treatment, and sometimes it can be very hard to switch from going all-out to save someone’s life to swapping to then provide a good death without that seeming like a failure, which of course it is not. There is absolutely no doubt that providing a good death is absolutely the core of what we should be doing.

I think there are a couple of ways that we can do that. The college of emergency medicine, with the College of Emergency Nursing Australasia, has released this week their quality standards, that involve some suggestions on the importance of end-of-life decision-making and end-of-life care for this area. In the training framework for emergency medicine trainees, they can certainly be examined on end-of-life decision-making. It is quite possible that come their final exam they could be set up in a clinical examination situation with an actor pretending to be a patient or a family member going through end-of-life decision-making. I think the medical colleges can have a contribution to that. It is harder when people have actually finished their training, but it is easier when people are actually going their training.

Mr MULINO — This might be outside your daily work, but do you think it could become more prominent in the general medical degree, the GP degree, without it necessarily being a whole course but something that is raised?

Assoc. Prof. BAKER — It could be, although these kinds of discussions are usually beyond what an intern or junior doctor would do. They need to know enough about this situation that when they accompany senior doctors and senior nurses in these discussions they understand what is going on and they understand the ethical and legal framework behind them. But the actual practical application of these will come as they go through their training, because they need more experience before they can do that.

Deakin University, which is the university I work for, in the medical school certainly has, as one of its four core themes, ethics and professionalism. I would say that our medical graduates are more aware of and conversant with the ethical and legal principles of end-of-life care and other ethical situations than most currently practising doctors. But they need to pick up the practical skills of actually when to speak and when not to speak, and where to look and where to have the discussion, and those kinds of things that really only develop during their training.

Ms PATTEN — I have another question. You are saying that more and more patients are presenting with an end-of-life plan or advance planning, which is a wonderful thing. How is it being presented to you? I know we have been talking about putting it onto — sorry, I am pointing to a screen that has got nothing on it. They have been scanning it onto the Trak system. They have been looking at different ways of incorporating it. Are you starting to see it on the Trak system or is it more likely that the carer has it folded up in their pocket and is handing over a hard copy to you?

Assoc. Prof. BAKER — Often we see it either in their medical notes from previous attendances, and often people attend hospital quite a lot of times in their final year of life. We see it in the documentation provided from aged-care facilities, and we see it on the alerts. If it is not there, we usually go looking for it as one of the first things that we would do, because it is such a key piece of information.

Ms PATTEN — In the last few days we have been in this region it seems that the organisations, Barwon and South West, have been really proactive in this area, which is very encouraging. Do you think it is kind of stand-alone down here? Is this area actually well advanced to the rest of Victoria, or are you seeing your colleagues in Bendigo and other areas also at this point?

Assoc. Prof. BAKER — I think end-of-life decision-making is at the front of a lot of rural doctors' minds. I think it is really a core part of their business. The community is a little older in rural towns, and I think they feel that it is a core part of their business. Sometimes I think they feel it is a core part of their business to protect their patients from overtreatment. With all the amazing treatments that are available there can be a tendency to want to do everything, but I think a lot of especially rural general practitioners look at protecting their patients and guiding their patients through a sensible approach to some of the high-tech elements of their medical care. Hopefully in most rural areas you will find it quite good.

Ms PATTEN — Yes.

The CHAIR — If I could just follow on from that, you have given us a bit of an insight into the emergency department — some of the challenges you may face in understanding the issues for a particular patient when time is scarce and access to medical records may not be available et cetera. The committee will be looking to make recommendations at the end of these hearing processes to the Parliament. I would like to hear more from your perspective as a practitioner in a dynamic environment. You just mentioned the difficulty in making the

transition from providing a range of services to perhaps providing comfort and support. Do you want to talk more about that and about what sort of changes need to be made in practice to make that effective?

Assoc. Prof. BAKER — I did not talk so much about the major department setting, but in our emergency department setting I think we are now moving to have the palliative care services involved even in the emergency department, where once they would not have come to the emergency department. They provide not only a different focus and like to work with us, but also provide different treatment options for keeping symptoms under control and for getting different people involved. So I think a lot of hospitals are moving to have their palliative care services involved in the emergency department.

But in the area that I talked about, the urgent care centres, I think it is important that they have immediate access to someone with experience in these matters, to talk through these matters. In general it usually needs to be a video access. It is still not the same as being in person, but if you can sit with a family and see their faces and they can see your face and you can talk about, ‘In this condition it’s not so much that your mother is sick, it is that she is dying and each organ is shutting itself down, one after another. We could take her to intensive care, but the chance that she is going survive is very small and the chance that she is going to recover to anywhere like her previous level of function is very small’. So the recommendations I am keenest on to start with would be to have palliative care advice for these situations through the retrieval services, because they are the people who are going to be contacted with anyone facing death that they are considering retrieving.

That makes it easier to train a small number of people than to train everyone at all 45 services, and for them to have that access to videoconferencing at all the services, which helps when they are providing resuscitation as well. It is incredibly important for that. But it also helps for these discussions with family members, which really are better face-to-face, but at least the video is much better than on the telephone.

Ms PATTEN — Some of the people that we have spoken to previously have talked about the double effects of providing relief to comfort the patient that may hasten death. They have said that in some ICU settings or even palliative care settings nurses have been very nervous about providing that treatment, and doctors also have expressed some concern about possible future litigation or criminal charges. Is that a concern that your colleagues are expressing at all in rural settings?

Assoc. Prof. BAKER — I do not think in emergency medicine settings I have experienced that, and I certainly do not feel that myself. Most emergency settings are very familiar with the drugs that are used. We are fairly good at controlling them to get the relief without getting extra sedation, but I think we are also aware that the extra sedation might shorten people’s lives. I think we are fairly comfortable that if the control of pain in some way shortens someone’s life, then that is part of clinical practice too.

Ms PATTEN — Great. Thank you.

The CHAIR — Professor Baker, thanks very much for your presentation and your evidence this afternoon. It was much appreciated.

Assoc. Prof. BAKER — You are welcome.

Witness withdrew.