

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Bendigo — 12 August 2015

Members

Mr Edward O'Donohue — Chair

Mrs Inga Peulich

Mr Cesar Melhem

Ms Nina Springle

Ms Fiona Patten

Staff

Secretary: Ms Lilian Topic

Research assistants: Ms Annemarie Burt and Ms Kim Martinow

Witness

Dr Jason Fletcher, Staff Intensivist, Advance Care Planning Clinical Lead, Bendigo 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 Dr Jason Fletcher, Bendigo Health staff intensivist, advance care planning clinical lead. Welcome, Dr Fletcher. Thanks very much for joining us.

I caution before we start 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. We have allowed half an hour for your session this morning, so I invite you to make some opening remarks and thereafter the committee will have questions. Thanks very much again for being here with us.

Dr FLETCHER — Thank you, and thanks for the opportunity as well. I have just put together a very quick presentation addressing some of the questions, particularly around the medical side of this subject. As you said, I am the director of the intensive care unit and the clinical lead for advance care planning at Bendigo Health.

Visual presentation.

Dr FLETCHER — For the medical profession there is no clear definition of when end of life commences. This will probably change as more research into this field is being done, and there are some definitions and also some diagnostic criteria that have been developed. It will probably end up being somewhere around six months. The way we generally approach it in the medical field is if you would not be surprised to read their obituary. That is how we talk to the junior doctors about it.

For the medical profession it has become an issue because society does not have all the resources, to treat everybody. That is what we call distributive justice — using the resources in a fair way. And also about respecting patient’s autonomy and transitioning from a less paternalistic model of care — about doctors telling patients what treatment they will get — to giving patients control and autonomy about what happens to them at the end of their life. The patients often do not know that they are entering the last stages of their life, and we need to avoid prolonging people’s death and actually promote people’s quality of life, not just their quantity.

The options we have got open to us are advance care planning, which is a relatively new field of about 15 years in Australia; palliative care; supportive treatment for chronic diseases, so people instead of having dialysis are getting supportive management of their renal failure; and also short trials of treatment with clear boundaries and then withdrawal of care if we do not meet the patient’s needs or goals.

In my personal opinion there are too many deaths in hospital, which is contrary to what people want for themselves. Most deaths in hospital are not unexpected; they are anticipated deaths. This is some data that we have collected at Bendigo Health. About 90 per cent of deaths are either expected or anticipated due to admitted with a terminal illness and to receive palliative care, which may well have been able to be delivered in the community, or they are not unexpected, so no-one was surprised that these people came into hospital and died. Almost 90 per cent of patients are expected to die or not surprised that they died when they came through the front door of the hospital. These are anticipated events that I think we as a community can do better in addressing.

The next question is what our medical practice currently is to assist people. In the hospital setting we use advance care planning, so getting people to document what their end-of-life wishes are. Unfortunately it is not very well funded at the moment. There is one person and a little bit of me to do this for the whole of the community, and it is in my opinion the wrong area. This is something that needs to be addressed primarily in the community, not in hospital when people are under stress and anxious and often lack the capacity to document these end-of-life decisions. The other thing that we do in hospitals is resuscitation planning — what we would do if someone had a cardiac or respiratory arrest — but these are reactive and done by people who are not necessarily familiar with the patient rather than being done by the GP. That is one of the weaknesses.

We need to make the diagnosis of dying. We need to be frank when that happens and tell people that, ‘Actually you’re dying and that process has begun’, and then need to focus on a relief of symptoms. What I mean by balancing the needs of the family with that of the patient is not prolonging someone’s death so that people can come from somewhere else, particularly interstate, while that patient is dying and prolonging that active

treatment waiting for family to come. That becomes quite a difficult moral and ethical balance of looking after the patient while trying to look after the needs of the family.

My suggestions would be that people need to be offered advance care planning when certain criteria are met, and this should almost be a KPI, to say that once certain triggers have been met, not necessarily just stage but also with regard to certain diseases, that people should be offered advance care planning — not made to do it but offered. We should expand the scope of refusal of treatment certificates, and when someone does in good faith complete an advance care plan, they should be legally binding in the same way that refusal of treatment certificates are — that is, if a doctor is aware of someone's wishes and acts contrary to them, then there should be repercussions.

That is one of the issues with advance care planning; they are non-binding in Victoria. We should seriously explore the concept of people opting in for cardiopulmonary resuscitation in hospital, because the current outcomes for people who do have in-hospital cardiac arrests are terrible. About 6 per cent will get out of hospital without any neurological injury, and only about 15 per cent will actually get out of hospital at all. A lot of CPR is done on people who will never benefit — elderly people with chronic diseases — because it is an opt out and people have not had the time or the opportunity or have forgotten to discuss resuscitation planning. It is quite stressful for people to have that discussion and quite a big use of resources to talk about every patient every time they are admitted and what they want done if they deteriorate.

Some more education for family and patients and clinicians and some more — we do not have a good feel as doctors what the natural progression of diseases are. We know very well with cancers what one and five-year survival rates are, but there is not a good feel for how other diseases behave. That really will inform us as to how aggressively or non-aggressively we should treat people with other non-cancer diseases. That is all. Thank you.

The CHAIR — Thanks very much, Dr Fletcher, for your presentation. If I could start the questioning by just going to the point you made about there are too many deaths in hospital. We have heard evidence from other locations and other submitters about the community's desire in general to die at home but how it often does not work out that way. Would you like to just provide more context to that from your perspective and what the drivers of that are? Is it inability to access services, or is it a change of mindset once in hospital, or is it indeed people not having thought about these issues before they find themselves in hospital?

Dr FLETCHER — I think it is a combination of all of those things, of a lack of resources for community palliative care, but I do think the biggest driver is a lack of understanding of patients of where they are in their disease trajectory, and I think that is potentiated by the fact that it is harder for a doctor to have that discussion than it is to provide treatment. It is a lot more time consuming, so it is easier for me to write a script or do a test than to sit down and have a discussion about, 'What are the goals of treatment? What can you reasonably expect in the next 3, 6 or 12 months of your life?'. So I think it is primarily in education.

Just the way the system is set up at the moment, a lot of it is volume-based medicine, so clinicians lack the time to have those discussions. And they are hard discussions. It takes a lot of courage to be able to say to someone, 'Actually, you are in the last 3, 6 or 12 months of your life'. I think it is less of a palliative care issue but more about that patient-doctor interaction.

Ms PATTEN — I was interested in your thoughts of expanding refusal of treatment. That has been mentioned from time to time. At the moment obviously it is for people with terminal illnesses. How would you see the refusal of treatment? Where would we expand it to? You also mentioned the notion of making advance care planning legally binding. What would be the difference, in your eyes, of those two if they are both legally binding?

Dr FLETCHER — They would probably be one and the same actually in that someone who has the capacity to make informed decisions if they do not want a certain treatment, regardless of whether it pertains to a current or potential future illness, they should be respected. At the moment we allow people to opt out of treatment in hospital provided that they understand the repercussions of those decisions, and I think that should extend to people in the community for a potential illness. So they would probably end up being one and the same.

Ms PATTEN — So we would have an advance care plan that was binding like refusal of treatment is now.

Dr FLETCHER — Yes.

Mr MELHEM — Thank you, Dr Fletcher. How does Bendigo and the region compare in terms of access to resources for end-of-life care, and as a supplementary, are Victorians aware of their choices?

Dr FLETCHER — I cannot comment specifically about how we compare elsewhere. I do know that we did have to fight very hard to try to get funding to have one advance care planning coordinator in Bendigo. There were a few major hospitals around Victoria where there had been funding historically and then there seemed to be a line in the sand drawn a few years ago where there was no more funding forthcoming. That was funded internally by the hospital. We have put in submissions for more funding, but that has not been forthcoming from the regional office. I am not in a position to comment about palliative care — how we compare elsewhere — just about the advance care planning resources.

Mr MELHEM — As a follow-up to that, do you think you have enough resources, for example, to be able to give individuals choices in relation to an active care plan and how to make a decision?

Dr FLETCHER — No, there is not enough. There is too much of a focus on in-hospital care and not enough focus on pre-hospital or primary care, and primary care needs to address these issues.

Mr MELHEM — Is that funding or legislation? Is that because of the law, or is it money?

Dr FLETCHER — No, I do not think it is because of the law. I think it is the way that the system is funded, and maybe it is the interface between commonwealth and state funding. The hospital gets paid to treat people; they do not get paid to not treat people — to prevent patients coming into hospital. It helps access but it does not help their bottom line necessarily. So there are different drivers and different funding mechanisms as well. But the simple answer is that we do not have enough resources to look after these people beforehand and stop these things happening.

Ms SPRINGLE — I do apologise for my tardiness.

Dr FLETCHER — That is okay.

Ms SPRINGLE — Forgive me if I ask a question that you have already answered or that you have already covered in your presentation, but looking at the slide we have up there, I am very curious for you to unpack no. 7 for me.

Dr FLETCHER — Yes, I did not talk to that. This is my personal opinion. The number one thing, as a community and as a medical profession, is that we should respect patient autonomy, provided that it is informed and without coercion and we are assured that the patient has capacity. I think there is a very, very, very small group of people where euthanasia is a valid option. I see it very, very infrequently in the acute hospital setting. In 20-plus years of medicine I have been asked twice, both in a palliative care setting as a junior doctor — I have never been asked in an intensive care environment — to provide euthanasia, but I think we should respect a person's autonomy, and that is why I think that is a valid option. But I think the uptake of euthanasia would be quite small.

Ms SPRINGLE — Do you have an opinion about a structure that could be put around that as an option? Taking into account that I guess law making is not in your realm of practice, what sort of legislative framework might that look like?

Dr FLETCHER — I think, no. 1, it needs to be patient driven, and there needs to be vigorous assessment by people — doctors — to make sure that the patient has capacity, and those people have no conflict of interest with providing that choice about euthanasia. I think they are the main things — that is, if there were a patient at Bendigo Health who wanted euthanasia, someone who was employed by Bendigo Health could not assess that patient's capacity, because that could then be seen and possible that the driver for that is to reduce the resource requirement placed upon Bendigo Health by that person. There needs to be a clear separation. They would be the most important things for me, and probably terminal should be restricted to a physical rather than a psychiatric illness.

Ms SPRINGLE — Thank you.

Ms PATTEN — Just following on from Ms Springle’s question, would you see that voluntary euthanasia could be included in advance care planning in as much as quite often advance care planning is about refusal of treatment, so where physician-assisted dying and voluntary euthanasia would be a more proactive approach?

Dr FLETCHER — One of the historical pieces of baggage that advance care planning has had to have, particularly initially, was about its association with euthanasia. I know sometimes when it is discussed on radio some people call in and say, ‘What’s the difference between this and euthanasia?’. So I think pragmatically they should be separated out.

Ms PATTEN — That is a really good point.

Mr MELHEM — Just following on from that, the whole idea of this inquiry started with the discussions about voluntary euthanasia. As we hear from people there is more focus on how we have a good end of life for people and voluntary euthanasia is ranking as a small part. Can you give us some examples? And I get it. You are talking about, ‘Let us look at how we can have a good death’, I suppose.

Dr FLETCHER — Yes.

Mr MELHEM — And euthanasia, let us just park it there for the time being. Is that what you are saying?

Dr FLETCHER — In the acute hospital setting euthanasia is a very, very small part of the system. I suspect it is a little bit turned around in the community, that it is a bit more of an issue in the community, in that I have not been approached in intensive care to have voluntary euthanasia. We are providing active treatment, so it is more about the withdrawal of treatment. I think it should be addressed, but I think it is a much smaller issue than providing a good death for people.

The CHAIR — Dr Fletcher, could you just give perhaps some description of the people you see at Bendigo Health? You have a big catchment. Could you perhaps just talk to that diversity of people who come to Bendigo Health and some of the challenges that can present?

Dr FLETCHER — Okay. In the intensive care setting I see every critically ill patient within our catchment area except for some discrete illnesses, so major trauma, neurosurgery et cetera — we do not do that here. Everybody who is critically ill comes to the intensive care unit. We necessarily adopt ‘treat first, ask questions later’, because people are critically ill and will die without time-critical treatment. Most people who we take will benefit, and if they were able to provide consent, they would, but there is a group of people who either, one, we get subsequent history from the family who tell us that the patient would not have wanted this and we withdraw care and they die in intensive care; or two, we get subsequent history or information that leads us to believe that the patient will not benefit from intensive care, and in that instance we would also then withdraw active treatment in ICU. Both of those groups of people would die in intensive care. A proportion of those people will be flown in or transported in from remote areas, so they are coming away from their community unnecessarily to Bendigo.

The CHAIR — Could you have a guess, or do you have any idea, of how many of those people you see have some sort of advance care plan in place that can inform the health care that you provide?

Dr FLETCHER — Less than 1 per cent.

The CHAIR — Less than 1 per cent? Okay.

Dr FLETCHER — We have about 700 to 800 people a year, and it would be single figures as to the number of people who have an advance care plan. A small proportion of those we will find after the fact — they will be filed away in the notes somewhere. We are obviously trying to address that.

The CHAIR — It is a challenge.

Dr FLETCHER — Yes, it is.

Ms PATTEN — I think we are speaking to some other people later about how we get that advance care planning front and centre in front of you, in front of ambulances and the rest. In thinking about that, you were

saying that talking about advance care planning in ICU is probably not the ideal location. How would you see it expanding out in the community? Have you got an idea of what that would look like?

Dr FLETCHER — One of our ideas was to actually have an advance care planning outpatient clinic so people could self-refer in or GPs could refer in because they were complex cases or they did not feel they had the skill set. We were not allowed to have that: there was a directive from the department that we were not allowed to start up an outpatient clinic. Then a few weeks later there was a circular sent out to all hospitals that advance care planning clinics were not funded and that all advance care planning should be done in usual care. What they are actually asking is for orthopaedic surgeons to do advance care planning while assessing people preoperatively, which is just not reasonable and not how medicine works — it is not in their skill set. It should be community based, outpatient ambulatory based. The conversation can start in hospital. We give people brochures and so forth, but very rarely would we complete one in ICU because patients lack capacity when they are that sick.

Mr MELHEM — One last question from me. Dr Fletcher, going back to point 7, and I think you made reference to people who have a terminal illness, what would be your view on someone for whom doctors were saying, ‘Well, you are going to go in six months’, whose quality of life is gone, a lot of pain? Would you go as far as saying, ‘Let’s make it legal now. We can give that person a pill to go quietly and sort of peacefully.’? Would you advocate for us to go that far and pass the legislation so that we can give protection to doctors and patients in that situation?

Dr FLETCHER — Yes.

Mr MELHEM — And in other examples? You said psychiatric and mental illnesses, for example, would not qualify. So your recommendation would be restrict it to terminal illness but nothing else? That is my understanding of what you are saying.

Dr FLETCHER — I would exclude psychiatric illness. Someone for whom there is no prospect of curative treatment and whose treatment options have been exhausted.

Mr MELHEM — So, ‘I am tired of life, I have had enough. Physically I am okay — —

Dr FLETCHER — I would classify that as a psychological illness, not a physical illness.

The CHAIR — Thank you, Dr Fletcher. I think your colleague Professor Budge is going to join you at the table.

Witness withdrew.