

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Traralgon — 9 September 2015

Members

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Dr Jane Fischer, Chief Executive Officer, Medical Director, Calvary Health Care Bethlehem.

The CHAIR — I would like to welcome Dr Jane Fischer, chief executive officer of Calvary Health Care Bethlehem. Thank you very much for joining us this afternoon.

Before we start, I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to 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, and you will be provided with a proof version of the transcript in the next week or so. Transcripts will ultimately be made public and posted on the committee's website.

We have allowed half an hour for our session this afternoon. Thanks for coming at a time of convenience to us. I invite you to make opening comments, and we will have questions thereafter.

Dr FISCHER — Sure. I am also a specialist palliative care physician; I am currently CEO and medical director. I guess I was asked to present here because of our role providing specialist palliative care services mainly into central and east Gippsland, so I am very familiar with Cheryl and Nicola.

As an opening comment, in the context of this whole of inquiry into end-of-life choices — and not just coming from a Gippsland perspective because I have obviously worked in a range of different settings — I am concerned that we are considering changes to legislation and yet there are plenty of people in the community who are not receiving optimal end-of-life care and have not got the choices to make. If we look at it in a Gippsland context — but, as I say, I think a lot of what I am saying you could apply even within parts of Melbourne, but certainly other state jurisdictions because I am on a number of other bodies.

There are issues around inequity of access to specialist palliative care, and we have seen that in Gippsland. We have been working with wonderful people, but even with the model that we have put up, there are variable referral patterns. It depends often very much on your level of GP engagement whether they will refer. We know that most of the referrals and most of the people that we look after — and this is across the board — are people with malignant disease. Yet we know that people with chronic non-malignant have a really high symptom burden in that last year or two of life when they are incurable. They have a high symptom burden. They have lots of complex psychosocial issues. There are not sufficient and adequate discussions around advance care planning and goals that are happening with that group. There is the Indigenous group that was touched on. There is the CALD population. There is a whole range of people who are not accessing.

I think if we look across Gippsland, there are variable models even, so what we are providing is different to what is being provided in South Gippsland and is being provided in West Gippsland, so you have got variation there. The people down here have not got access to some parts of that specialist team that I would consider critical, and that is particularly around counselling, pastoral care and bereavement support, even some of the specialist allied health disciplines. So people in rural areas, and speaking from experience, are disadvantaged. They do not receive the same quality of care, and I think that they do a fantastic job.

Another issue is that there is a really variable level of knowledge about what palliative care provides at a medical and a health professional level. Once again, we have got some fantastic GPs who engage, who are part of the care team looking after their patients, who ring for advice. Then you have got others — even specialists — who will not refer, patients are poorly managed. If they do refer or ring for advice, it is often very late. You track through what has been done in not what you would consider a best practice sort of context. I think it is, one, about what does palliative care do, but it is also their own knowledge and how do they better support. As a system, we have to look at how do we build capacity in all of our health professionals to be providing? Because specialist palliative care cannot take on everybody, it has to be for the more complex, so how do we build better capacity across our system?

I think there are societal issues. We are quite a death-denying society. People do not want to talk about it. We often see people pursuing futile treatments, and sometimes that is on the advice of their health professional or their specialist team. Speaking from personal experience, having been involved with palliative care for 30 years, I have got so many stories where people were reluctant to be referred because there is this stigma that palliative care means you are dying, and yet people are actively living and wanting to still achieve goals. Yet when they are referred to us they comment that they wish they had actually been referred to palliative care services earlier because suddenly they were at the centre of what was happening, they did have choice. They do have choice about what treatments they want or do not want, what is important to them and their family at this time, and

how do we turn that into a positive experience, so I think that lack of community awareness is definitely an issue as well. I think sometimes that in itself prevents people accessing the right care.

Advance care planning, you were having a discussion with Cheryl and Nicola. I think there is still a lack of understanding about the role of advance care planning. I think there is a bit of a view that it is going to be a panacea, like, 'Let's introduce advance care planning and that will ensure everyone gets optimal end-of-life care', but it is not necessarily. There is certainly positive evidence that it helps to understand what people are wanting to achieve, but it does not necessarily guarantee that people are still going to get the access to the services they need and the good quality of palliative care. But I still think it is very important.

There has been some statewide policy and what have you, but it is often being almost pushed onto palliative care services. In my opinion that is actually happening a bit late. It should actually be happening much earlier down the track with people who have incurable disease, because advance care planning is an ongoing conversation and people's goals and wishes change as their journey continues. We are part of a trajectory and by the time they get to us, yes, we are still trying to understand their wishes and what have you, but having a formal advance care plan might not necessarily be the right thing.

My father was a case in point. Two days before he died my mother said, 'Shouldn't he have an advance care plan?'. And I said, 'Well, no, Mum, it's okay because we've all been talking and we know what it is that we want'. So it is not just about a document; it is actually about those discussions and who is advocating for that. I think that is important.

The other thing that was briefly touched on was also that I think we have inadequate models of support for carers. There is a lot of discussion about palliative care — people wishing to die at home — and I think that sometimes it is extremely physically and emotionally exhausting for people, so how do we have good models of support that assess carer needs, but also then put strategies and supports in place to support those carers — models of respite, those sorts of things. To me they are all issues. I think palliative care has come a long way, but it is not something that is still readily accessible to all for that range of reasons.

The CHAIR — Thank you very much for your opening comments.

Ms PATTEN — You have very succinctly reiterated a lot of what we have heard today about the inequity of access for palliative care, particularly in regional areas. But we have also heard some very passionate submissions from people. Previously we heard from a woman whose partner had multiple sclerosis and she felt that he could have been more proactive in his end-of-life decisions, so certainly there is the refusal of treatment but for that person to be able to say, 'Enough's enough' — and I think he could have had the world of care and the world of counselling but there was a point. We had another person here also with their 18-year-old daughter who was in a similar situation — the world of care, the world of counselling but there was a point when they wanted to be proactive about the time. Do you think that can fit into your notion? I do not think it is necessarily palliative care, is it?

Dr FISCHER — I certainly and I think palliative care considers that dying is really a normal part of life. But not everything is always perfect in this world, so how do we as a society really support those people who are disabled, who have a whole multitude of problems? The autonomy to say, 'I want it to end now', is that right as a society, I guess.

Ms PATTEN — Is it right to say, 'No, you cannot'?

Dr FISCHER — I certainly have concerns around how you protect a huge number of people. If we were in a different place where we knew people actually were accessing and having, you would say, 'Sure'. You have heard some stories and maybe those people have. But there are also plenty of people, and I hear of people, who have had terrible experiences. Then they have a totally different experience because suddenly there are a whole lot of other things that around their discussions happening and choices made. In all my years of working in this sector I could count on two hands the genuine requests, because I think sometimes people are in incredible distress and so then when you unpack that there are things that you can do. But there have been a very small number that have genuinely wanted, 'My life to end now'. I also have an issue as a medical practitioner, that I have trained to provide support and compassion and quality of life and those sorts of things to my patients, and to me to actively end someone's life is very contrary to those views.

Ms PATTEN — So something like terminal sedation would be within the range of providing care to someone?

Dr FISCHER — Yes, but do you know what? Even terminal sedation, as in really heavily sedating someone, is not something I have even done very often. It has often been about the discussions and people knowing. I think sometimes it is also people knowing what options there are. So if you have a complex symptom issue, ‘Okay, this is what we’re going to do now, this is the next step’, so there are a range of things that are there. I think what is much harder to deal with, and that is probably more of an issue than the physical symptoms, is the psychosocial. Is pushing a button the right thing really? Are we really dealing with someone’s distress by doing that?

Lots of conflict that we see within families, and I think a lot of what we do which I think makes it complex, is actually dealing with the different views within families. Some of that comes about because people do not want to talk about dying, so often what will happen is that the patient is ready, the patient is comfortable with where they are at and the family is wanting everything done to keep this life happening and continuing. That can happen in that really severely disabled context too I think where people cannot let go. I think it is allowing people to die as well.

Ms PATTEN — Thank you.

Mrs PEULICH — Two questions, Dr Fischer; thank you very much. Retirement villages have independent living units right through to high-support beds. Palliative care seems to be misunderstood. We have all heard medical practitioners not quite understanding the brief of palliative care, and I think the common person’s understanding is that once you have been diagnosed with a terminal illness and you are approaching end of life, that is when it becomes applicable to it too. Does palliative care need a new name or does it need to be better explained and promoted?

Dr FISCHER — I do not think, and I have sat on peak bodies, boards — —

Mrs PEULICH — I can see that, but I thought I would ask you a provocative question.

Dr FISCHER — We have these discussions, believe me. I do not think changing the name is going to help. I think we have got to start having discussions in our community about how we build resilient communities. Yes, people can discuss and know how to interact with people who have got a terminal illness, find out what is important to them and how we provide support and make that a positive thing. I do not think changing the name — —

Mrs PEULICH — I just thought I would ask.

Dr FISCHER — Yes. It comes up, and it comes up internationally. Do we call it supportive care and then cancer care and supportive care to what they do?

Mrs PEULICH — But it certainly does seem to be misunderstood or not well, you know. My second question is probably more pertinent to some of the evidence we have heard this afternoon, in particular from the case my colleague here referred to, the submission made by Terri Eskdale in relation to her partner, who was a sufferer of multiple sclerosis and who sadly took his own life. He was riddled with pain and wanted to pre-empt a point in his life when he may have been unable to take that action. Given your specialist experience and the fact that Calvary Health Care Bethlehem has a statewide role in caring for those with progressive neurological disease, are there people with neurological diagnoses or life-limiting diseases whose pain can be managed to the level where they are not driven to commit suicide or contemplate conditions for that?

Dr FISCHER — I think this comes back to the fact that sometimes it is more the existential distress rather than the physical pain. Yes, sometimes, but in my experience it has been rare. Dealing with a progressive neurological group of patients getting pain under control has been a significant issue seeing it is often dealing with increasing disability, dependency on others, but — —

Mrs PEULICH — Especially if you are a male, I guess?

Dr FISCHER — Yes. But then I can play you a DVD that we did with some schoolchildren who interviewed some patients, and a patient with MND said that knowing that he was going to die from this was

quite liberating and, he took a totally different view on his life and what was important to him. I think you get lots of different stories.

Mrs PEULICH — You may not have had the chance to have a look at the submission, and it may be possible for you to take a copy of it. It seems that Mark Brennan endured an enormous level of pain. Is this manageable? Can it be managed with good care?

Dr FISCHER — I have not seen the submission. As I say, so I do not know how much was through physical pain and how much of it was other issues that were contributing to that.

Mrs PEULICH — Experiential pain.

Dr FISCHER — Certainly in my experience sometimes when we are struggling with controlling with someone's pain it is often all of the other psychosocial, existential and spiritual distress that are making it difficult, so I think that that is our challenge.

Mrs PEULICH — Any thoughts on that front?

Dr FISCHER — To me, it is about some of that broader society approach to how we are having discussions and working with and supporting these people. But no, I do not think there is an easy solution. It is interesting when you have people who have had an awful experience that you can turn that around so they can then go and be your best advocates in fact. I guess the thing is you are not going to always get everyone 100 per cent.

Ms SPRINGLE — We heard earlier from a physician who talked about using terminal sedation — not regularly, but it being a thing that he has done on several occasions. We have also heard in other testimony that this stuff is happening anyway. Would a legislative change really make that much difference to what is actually going on on the ground?

Dr FISCHER — I come back to saying that these are GPs; these are not specialist palliative care physicians necessarily. I have had discussions with doctors who think, 'Oh well, we will just crank up the morphine', you know. And yet I am actually saying, 'You know someone is actually dying, so why are we not responding to their symptoms and giving them the medication they need to be comfortable?'. There is a normal process that is part of that dying process. You can still be giving people adequate opioids and other drugs that are keeping them comfortable but which are not necessarily hastening the dying process. I think some of it is a lack of knowledge, though, as well amongst medical practitioners.

Ms SPRINGLE — In what way?

Dr FISCHER — Because they do not know how to administer the drugs and the medications and deal with the issues in the proper way. So their only response is, 'Oh well, let's hasten this', because they are not comfortable with the whole death and dying thing either.

The CHAIR — Dr Fischer, thank you very much for what you had to say and, as Mrs Peulich in particular brought to our attention, your experience in this field. We appreciate your time and evidence this afternoon. A transcript will be with you in the next week or so.

Dr FISCHER — Sure.

Witness withdrew.