

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Bendigo — 12 August 2015

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The CHAIR — I would like to welcome Ms Elizabeth Loughnan, the acting manager of Loddon Mallee Regional Palliative Care Consultancy Service. Thank you very much for joining us this morning. I caution you 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 placed on the committee's website. We have allowed half an hour for our session today, so I invite you to make some opening comments, and thereafter the committee will have questions. Thank you again for being with us this morning.

Ms LOUGHNAN — I am here to represent Bendigo Health, as you know. I am part of the integrated palliative care service. We have three departments within that — hospice, which is not represented today, which has 10 beds, then we have the regional consultancy team and the local Bendigo community team. As far as the region goes, our region covers 25 per cent of Victoria — a huge area to cover. Our particular team covers the southern end, so from the level of Swan Hill down. We do have issues with borders, whether it be the river or whether it be with other services on multiple sides. The distance is huge, as you would imagine. We provide care throughout the region through videoconferencing, phone contact and all that. I am starting to lose my voice already! So it is a small team. There is now a full-time palliative care physician who has recently been appointed and a nurse practitioner. We are about to appoint an aged and disability palliative care nurse and we have minor administration and also coordination support.

From the local perspective, our community team covers the greater city of Bendigo, and we also cover within about an hour's drive from Bendigo. With the growth of Bendigo in recent years, we look forward to the new hospital; however, with that will come further demand. Our teams cope with rural driving as well as the peak hour traffic that Bendigo now suffers. It does affect the service that we provide.

As far as end of life goes, we are the specialist palliative care teams, so we are at the more complex end of the care. I think the language probably needs to be around a 'palliative approach', not that we are palliative, as such, because it is about the goal of care right now. When you talk about a patient presenting to ED or ICU, it is about what is happening right then. The end-of-life care discussions need to happen much further back than that, and they need to be continuous and to be revisited. When a patient goes to their GP, I believe — that GP assessment that they are entitled to every 6 to 12 months — it should be brought up each time, because our carer profile has changed; there are fewer carers out there due to work commitments, there are also ageing carers, and there is change with the carers. Your wife or husband or whatever may suddenly be diagnosed with dementia, so your plan will have to change.

I think at that time we also need to look at respite options, so when the GP looks at that sort of thing — I am not saying they do not do it now; I am just saying it would be good if they looked at ACAS straight up — that it be discussed for anybody over 65. We certainly have gaps for respite under 65. Our youth and anybody between 25 and 55 really do not have many options. Our community team run a day respite program, which is run three days a week. It badly needs extra funding. It does not even have a permanent site. We rely on volunteer assistance, and volunteer assistance is fine, but if you want to grow a program it is difficult.

We took the program for one day to Echuca to try it out in the region with the support of the Echuca volunteers and the palliative care service up there, and that was well received, but we could not do that on a regular basis — it was just a one-off.

There is not a lot of respite. Say with oncology — breast cancer — in this region, there is the Otis Foundation, which have places for women with breast cancer and their families to recover. We need something similar for youth. Our day respite program provides taxi vouchers for them to come. That really only services people in the immediate Bendigo area. If you live out at Newbridge, it is too far out for us to be providing that. So there is really not a lot to reach out to them. They need somewhere that is a very nice environment, which our hospice is, but they need something that is away from the hospital environment, in my opinion — somewhere better suited. I am rattling, I am sorry.

The CHAIR — No, it is great — thank you.

Ms LOUGHNAN — If you look at funding, yes, we need more on the ground. The community teams have the options of nursing and allied health, depending on the mix you have there. Our particular team is a small

team — probably only five nurses, as such; we have very small allied health team, we have social work and occupational therapy. It very much needs to be enhanced, because you need to be responsive to your patient's need. It needs to be immediate, it cannot be, 'Go on the waiting list for the rural health team' — the delays are too long. I do not know what else to say really.

The CHAIR — That is great, thank you. Perhaps we could ask a few questions that flow from that. I will start by asking you to give us a bit more background to the videoconferencing or how you are using technology to overcome the tyranny of distance because I think that is an important issue. There are obviously advances and it affects other regions as well, so I would be interested to learn more about how you are using technology.

Ms LOUGHNAN — From the technology side, I would say it is under-utilised. From the regional team, what we find is that the regional hubs are not well supported with backup for them. We certainly use Polycom and the consortium have provided iPads a couple of years ago — two iPads to each of the hubs — so we encourage use of that, but you cannot use that all the time. For that initial assessment of a patient, it is really difficult. You need to see them. Our patients, by then, are very complex, and that clinician needs to see them head to toe. So you cannot ever replace it totally with that. But yes, I do not think they have the ICT backup, really, for troubleshooting.

As far as our local team go, we use the hospital foundation. We asked them for money for our surface pros; that is how we got them. So there is really not a lot of funds in there for ICT replacement. Particularly for our teams on the road, I think they really need the best — whatever is available. Databases are difficult. Palliative care requests lots and lots of information, which is fine, but we need money to actually upgrade our databases to meet these needs, because every time DHS requests something, they request something that we have not actually been looking at. It is always, 'Can you see how many people have brown hair?'. Well, we were not looking at that. It is really difficult to be chasing your tail all the time.

Ms PATTEN — Thank you very much for that. You have painted a really great, solid picture. You were talking at the beginning about the words that we use around this — 'palliative care' or, you said, a 'palliative approach'.

Ms LOUGHNAN — Palliative approach.

Ms PATTEN — We have also heard from other people that maybe we need to call it something else altogether — that 'palliative' obviously means it is end of life, where sometimes 'palliative' does not, as we were hearing. It is end of life in 10 years or —

Ms LOUGHNAN — Yes. Some years ago I was involved with the rollout from DHS of supportive care screening to newly diagnosed oncology patients, and in amongst that you find that it actually starts a conversation of what your ongoing needs might be. I think that you can actually have those conversations at diagnosis for oncology patients prior to major surgery or prior to commencing chemotherapy as trigger points — for chronic disease it is a bit harder to pick, but it certainly should be before insertion of pacemakers, starting of renal dialysis and before continuous home oxygen is put in place. I think there are triggers in amongst it that should then get you saying, 'Where exactly are you at?' and 'Are you looking at your future and what your needs are to going to be?'.

Ms PATTEN — The word 'palliative' is something that people have indicated creates an uneasiness in there because people see palliation as —

Ms LOUGHNAN — Death.

Ms PATTEN — death. Whereas I think some of the treatments that you are providing are not necessarily that.

Ms LOUGHNAN — A palliative approach to our palliative services is about quality of life, so it is actually impeccable assessment and actually really optimal symptom management. We need to change that language, so that when you look at, say, funding what you can do and crossing over with chronic disease departments, you need to have shared roles where, say, a PEPA placement — I do not know if that has come up in your talk.

Ms PATTEN — No.

Mr MELHEM — No.

Ms LOUGHNAN — It is actually funding provided so that, say, if a staff member who works with HARP (Hospital Admission Risk Program) might like to see what specialist palliative care is about, they would be able to come and work between two and five days with the team. I think you could build bridges into getting that language used in different departments by actually saying, ‘Look, you can come for three months, if that is an option’, so that there is a strong bond between departments to gain the understanding of what we mean by a palliative approach — not that they are just palliative. Everybody is going to die. We have to normalise that, and that is what palliative care is about. It is about getting everybody on the same page. Sorry to rattle on.

Ms PATTEN — No, you are not at all.

Mr MELHEM — Do you think Victorians are informed, in your experience, about their choices about end of life and particularly in your region and in your experience?

Ms LOUGHNAN — It is something that people put to the back of their minds, so even if the resources are around them, I am not sure that until it is relevant that they are going to be thinking about it. In our particular region, say, if you are looking at what you are informed about and what you are planning for, we have had floods knock out hospitals and aged-care facilities where they have had to evacuate. You cannot plan for that. No conversation is going to actually sew that into it. I think we need to put palliative care out there as an early intervention and as one of the first services that is involved when people get a life-limiting disease diagnosis. I think it just has to be that they are around, they are in outpatient clinics to be drawn on if they are needed, because people are diagnosed at different stages. Some of them are really quite acute, so their choices are limited. You need palliative care on the ground, so that it can be a conversation straight up in amongst your options — that supportive care through a palliative approach is an option and not just seen as the last-ditch effort.

Mr MELHEM — To achieve that, would it require a law change or is it just a matter of education — educating the general public and educating physicians to achieve that?

Ms LOUGHNAN — I do not see any need for law change, because the law actually supports that the medical team would put in appropriate symptom management. People, when they have their end-of-life discussions, are talking about, ‘I want to be kept comfortable’. That is appropriate symptom management; it does not need anything further than quality symptom management. If you start those conversations early and they feel well supported, I do not know that they would be looking for anything further. And because you legislate for all, I think you run the risk, for people who are depressed or are frail or vulnerable or their health literacy is not very good, of leaving them open; anything could happen to them really. I think we have to support them more.

Ms SPRINGLE — Thank you. You talked about technology earlier. Can you give us a bit of an overview of any outreach services that you provide as part of the practice, because you have already pinpointed that, certainly in those initial phases, technology cannot replace the face-to-face diagnosis and consultation of health practitioners. So in your services, how much outreach do you do and is it resourced well enough? Is it meeting demand?

Ms LOUGHNAN — I do not know. I think you need a different recipe for services that are, say, close to Bendigo and Castlemaine, close to us, whereas Swan Hill is far away, so you need to look at them individually — the remote and the close. We have videoconferencing that our palliative care clinicians are involved with, like, say, the lung multidisciplinary meeting where you have all your treatment teams come together and they hear from Swan Hill and Echuca — all the hubs come together and discuss a way forward for a patient. I think that is well provided for and you will probably hear from others later in the day about that. I think that structure is really quite good, but I still think that on the ground there needs to be more familiarity with it. I do not know that it is well used really, but you have to have clinicians who are comfortable with it as well.

Ms SPRINGLE — That being the technology?

Ms LOUGHNAN — Yes. And that takes time.

Ms SPRINGLE — Putting that aside, my question is probably more about the face-to-face stuff that is outreach, that is not within a hospital or a day clinic or outpatients.

Ms LOUGHNAN — Currently our regional team is reviewing our service model as such. Our region is challenged by the fact that we do not have a central highway right through the middle of it where all the towns go off it. We have three or four networks, so we look at a cycle of how we can link to those services. We are working towards the development of clinics — they have to have the demand though. With this new physician, we are actually looking at what is going to be a fit that works in the big plan. That it is currently under review is all I can say really.

Ms PATTEN — What percentage of your clients would die at home? How many die at home who want to die at home?

Ms LOUGHNAN — Currently, for the last 12 months, around 16 per cent of our clients died at home. Of those who wanted to die at home, it can change as their needs go along and as things become too complex. I do not think our data reflects that. Certainly our VINAH requirements ask what their preference would be. It does not actually then pick up that — guess what? — they have changed and the reasons why they have changed. So I think that is a hard one to capture at this point; it is not reflected in our data.

Ms PATTEN — Would greater resources enable more people to die at home?

Ms LOUGHNAN — Absolutely. Our current community service works Monday to Saturday and after-hours contact is done through the after-hours nurse managers of our subacute campus. There is no longer a facility to go into homes after hours. That is security funding. I believe that leaves carers high and dry. I really do. So whether there is a criteria that you would meet where you would need to send someone out — and you would need to send two staff, I would think — and whether it would involve home nursing plus palliative care to actually meet the appropriate need of the time, but I think that for carers in this particular region that is a risk. They are not well enough supported.

Ms PATTEN — Thank you.

The CHAIR — Ms Loughnan, thank you very much for your evidence today and for your perspective. As we said, the Hansard transcript will be with you in the coming days. We thank you for joining us.

Ms LOUGHNAN — Thank you.

Witness withdrew.