

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Warrnambool — 30 July 2015

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Ms Fiona Heenan, Director, Primary and Community Care,

Ms Jeanette Beaglehole, Community Palliative Care Volunteer, and

Ms Lyn Smith, Community Palliative Care Volunteer, Portland District Health Service.

The CHAIR — I would like to welcome Ms Fiona Heenan, director of primary and community care, Ms Lyn Smith, community palliative care volunteer, and Ms Jeanette Beaglehole, community palliative care volunteer, from the Portland District Health Service. Thank you, ladies, for being here today.

Before we invite you to speak to us, I will just caution 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 45 minutes for this session this morning. I invite you to make some opening remarks and the committee will have questions thereafter. Thank you again for being here.

Visual presentation.

Ms HEENAN — Thank you for the invitation. Portland District Health also put in a submission through Palliative Care Victoria online. They requested our input so we submitted as members of that. Portland District Health is a rural health service located in south-west Victoria in the Glenelg shire. We have a population of about 10 000 people. We have a reasonably low SEIFA index, which measures disadvantage, in some pockets within our community and to the north in the Glenelg shire, which has a population of about 19 000 people.

Our area is predominantly logging, a deep sea port, primary industry, cattle, sheep farming and so forth. We have only 1.2 FTE palliative care nurses employed within our area from Portland hospital. Otherwise the service is supported by community health district nurses. We are also members of the Barwon South West Region Palliative Care Consortium. Being a member of that consortium has allowed us to have the capacity to provide an out-of-hours service overnight. We did not have the capacity to do that and employ on-call nurses and so forth, which we had tried in the past. That is provided through St Vincent's Hospital and Caritas Christi.

Portland District Health, which has about 60 beds, does not have an emergency department. We have an urgent care centre with about six trolleys. We have only one palliative care inpatient bed, so it is predominantly managed from the community.

Last financial year, being a small organisation and community, we had 201 clients in the service officially through palliative care. It is not everybody. We have other service providers in the region such as Casterton Memorial Hospital, which is about an hour north of us. We also have the Dartmoor Bush Nursing Service and Heywood Rural Health. Their district nurses provide and are trained. There was a total of 722 hours of palliative care, which is quite small.

One of our major areas and drive is based on the Department of Health and Human Services advance care planning framework. PDH has a policy in place. We undertake regular surveys with Victorian Palliative Care. We undertake the Victorian Palliative Care satisfaction surveys as part of monitoring our performance in these areas, such as advance care planning. I will leave it at that.

All our palliative care patients are admitted under the palliative care program where possible. They have a statement of choices and it is an ongoing discussion that these ladies witness. We also talk about enduring power of attorney and financial power of attorney.

Our advance care plans are flagged on what we have as a new electronic medical record system, which goes throughout the Barwon south-west. This is going to be a game changer because of point of entry. So whether they come through the emergency department at South West Healthcare — and you will probably hear from Tim from ED that people are flagged at Heywood, for example, because that is one of our catchment areas — we now scan advance care plans. There is an alert system put on, so whether they come through Trak and emergency department presentations, it really does support that continuity of care. We have just gone live as of 1 March, and we are still refining that system, but it will make a difference.

Identifying gaps through the advance care planning and the audits is about asking the question and documenting. The urgent care centre has now an MOU at PDH with the aged-care providers within the region, which includes Harbourside Lodge and Bupa, which is a 90-bed private facility, and Heywood Rural Health.

They will send their advance care orders or statement of choices with their client, or it does get scanned onto the system. So it is not everybody; it has been a work in progress putting people onto Trak.

We have a number of advance care practitioners, and we have added to that. It has traditionally been through our HARP or chronic disease programs, palliative care, but we have also recognised in urgent care now that we have a number of nurses trained, and also through our counselling team, generalist counselling team, and also our AOD, alcohol and other drugs. So depending on what trajectory you are, we will be trying to address that moving forward.

One of our new tools that we have piloted within the consortium is the CSNAT assessment tool, which stands for the carer support needs assessment tool. We recognised that our carers worked through audits and statewide surveys and that they were perhaps being overlooked, more so being very patient or client centred. As part of that recent pilot over the last 12 months — it started in April 2014 — up to March this year we had 55 participants within that, and we just wanted to trial the tool. Twenty-eight of the registrations was not complete, but with the remaining 27 of those that were complete 20 people stated they were happy and pleased and that their needs had been met as a carer, but only 7 — so a very small sample size — said that their needs were not met.

Within that PowerPoint presentation there are a number of actual aspects that were drawn out of that. Perhaps with a larger population to analyse and pilot the tool you would see a different result, but you can get a bit of a sense and a snapshot — getting a break overnight and knowing what you are going to expect into the future, which is really, really difficult. We were talking about this in the car.

The CHAIR — Ms Heenan, can you leave a copy of this?

Ms HEENAN — Yes, I have; Kim has a copy of that.

The CHAIR — Thank you.

Ms HEENAN — Equipment was another issue as well, which we now have; our physio and OTs are seen as part of that rather than strictly a nursing and district nursing team. So it is more multidisciplinary, and you can see that coming through our audits — through the satisfaction audit for 2014 — that that was quite good. It is still a work in progress.

In some of our priority areas — and I am just about finished — for us is we have the PERM database, which is for palliative care across our region. It had been planned for implementation about two years ago. It has been live and has continuously been refined. One of the things is that this database informs our funding bodies and goes back to the Department of Health and Human Services. We were recently questioned by the Barwon south-western region of the department of health regarding some of our data outcomes for preferred place of death. When we run the PERM report you can see — and this is just one that we ran recently — it shows that people are not being asked about their preferred place of death; it said 38 people. Last month we reviewed that and proved that it was not correct. We reported it back to the Barwon south-western region of the department of health, and the central office has now indicated that they acknowledge that, and it is work in progress. But I can just show you that at that last report really 17 of those people had not been asked, but 23 had. So there is a big difference.

Then drilling down, we know that some of those people are deceased and their histories are now parked and stored away, so we would have to pull them out. But we suspect that the majority of them have been asked, and our palliative nurses say they do start that conversation. Sometimes it is end of life, and that is when they are called in — it is a late referral — so sometimes you have not had the opportunity to establish that rapport with those clients and have those conversations, so it may have been omitted. It is about getting the pain relief and the multidisciplinary team involved.

Last of all it is down to our palliative care volunteers. That is the photo of our last graduates. In 2010 — and this is a Palliative Care Victoria program at Western District Health Service, which I am sure you have heard about — we had six palliative care volunteers in the project. Over time people are leaving the district and retiring from volunteering. We have just run another program, so that brings our numbers back up to 14. The feedback and evaluation is that they do value add to the service. Our volunteers give their time every week for the establishment of their rapport with the families and to actually give some respite as well when our capacity

is limited is invaluable. That is really all from me. I do not know if you want to mention about how you found the program and the benefits of the palliative care program?

Ms BEAUGLEHOLE — I was very thrilled to be part of that first group that were trained. We were ward volunteers, and all of us who were ward volunteers and volunteering in other ways were given the opportunity to do the palliative care training in 2010 — to start that. I was quite thrilled to be in that training. It was fantastic. We got on very well. We shared. We had really special people come in to help with the training, locally and from further away, and certainly some from over here in Warrnambool. It was all very special. At the end of it we then just waited to be matched with our first palliative care patient.

The palliative care nurses in Portland take a great deal of time and put a lot of thought into which volunteer they will match with which family situation. It is a hugely important part of it. My experiences have all been fantastic in that respect. I have been totally matched perfectly with the family and the patient, and my experiences have all been really, really good and very special. The very first one was with a lady who loved playing scrabble — ‘Yes, yes!’. So each week we would sit up and have a game of scrabble and a cup of tea and conversation for as long as that was possible. As things changed, what we did changed, and likewise in other situations too.

From what you did at the very beginning, as the condition of the person slipped, you changed what you did, but it was always a privilege to be there and usually a weekly commitment, sometimes an extra. Sometimes you would be taken out to be introduced to somebody, and that person thought no, they did not deserve to have someone extra come in to keep them company. Sometimes you would be taken out, and the next thing you would know it was such a last-minute thing that that person had departed after all and you were not needed; they had died before you had a chance to actually interact and share with them. So each one has been different. Each experience has been different, but because we have been matched so beautifully and well, it has been a privilege to do that.

Yes, we are there as an opportunity to be somebody else who listens to what they might want to talk about — maybe not what they would talk about with their nurses in a caring situation or do not want to talk to their family about. We are there, and you can become very close. In addition to all the pages and pages of training you do, you form your own bond with that match-up you have been given, and then you just learn to interact in the way that is right in that situation and, to a certain extent, forget all the training pages. You just interact in that personal environment you are in, but then at the same time you remember that you need to have that one step away — just one step away — because you are there in a formal manner, and that is something that you become better at along the way. So it has all been really special. The one I was matched up with for the last part of last year was a real team situation. She was at home. They were a very small family group from another part of the country and she wanted to stay at home if possible, right to the end, which did turn out to be possible, but her care was a huge challenge for the district nurses and the palliative care nurses. I was really privileged to be part of that team. Her care was something quite unique for the nursing team in the hospital, as I understand it.

In another care situation, which Lyn has been part of, I was matched up with this lady, a younger lady. She and I shared a very keen interest in craftwork, so it was a privilege to go and talk about all sorts of things, but craft was always there. After about 12 months the situation for me had become too close, and I thought, ‘I can’t be a palliative care volunteer visitor here now. I need to change’, because I was sort of too close. I said to the palliative care nurse and coordinator, ‘Okay, I think it’s time for a change for this lady and for me’. So Lyn has taken the position that I had and on a Monday night goes out to this lady’s house and shares in a way different from what I did. So we are supporting that lady in an ongoing way. She is a younger lady — huge determination but there are really difficult physical aspects of her situation. Everyone is different, and you get something different out of every one. It is very special.

The CHAIR — Thank you. Do you want to say anything, Ms Smith?

Ms SMITH — I think it has been covered.

The CHAIR — Thank you very much for those remarks; it is very much appreciated. Ms Heenan, we have heard about the challenges in some of the rural areas and Warrnambool compared to some other parts of this district. From your perspective in Portland, can you perhaps identify some of the challenges that you encounter in providing service, given that some of the communities you service are quite isolated and quite remote?

Ms HEENAN — Yes. There is distance to travel and to drive, and under the home and community care service, for example — HACC — for district nursing, that time is downtime. It is not counted towards their targets as direct or indirect patient care. I think that is really unfortunate. Portland, not so, while we are within the town boundaries, but potentially when you are driving to Heywood, it is half an hour to that township. If you go beyond that to Drumborg — some of us have to go up to Dartmoor — that is an hour there and an hour back. We certainly involve the local nurses, whether it be the bush nurses at Dartmoor, but they are not trained clinical nurse consultants. There is only 1.2 EFT. One of our staff is off now on leave, so that puts pressure back onto our system. You have to do a lot of planning, where you can, as part of that.

I guess it is that isolation and making sure that we have a capacity-building approach to what we do so that your workforce is trained appropriately, including general nurses, and that palliative care is their business. Also, GPs are often at the front line and are quite pivotal, so they need to be confident and competent in provision of palliative care and also with prescribing medications, Niki pumps, and knowing their technology and setting those up and so forth. Some of our clients have lines put in — PICC lines — so you need to have staff who are trained in how to change those and manage those. It is just not subcutaneous and so forth.

Having an appropriately trained workforce is a big challenge in the rural areas. Typically to go and do training you may have to go to Geelong or Melbourne metro. Also with the networking meetings as well, we start to use some of this great technology that we have for videoconferencing and teleconferencing. Early assessment, comprehensive assessment and a multidisciplinary team approach is really important. It has been fantastic now that we have a visiting oncologist service and chemotherapy — not all chemotherapy — and that is being conducted, and I know it is like threefold from what they anticipated in the first year. People want to have their services closer to home, typically because their family is there. That they feel comfort and are surrounded by their loved ones is really important — and not having to move.

If I take my directorship hat off and put on my consumer hat, my father died of cancer of the prostate at the age of 55, 20 years ago as of 30 June. A lot of his palliative care and treatment was down in Geelong, and we had to drive him up and down. He had bony secondaries. He had fractures. Just to be moved on a road and the discomfort of all of that — thank goodness things have changed now and we have the use of telemedicine as well, and this is going to be a growth area for us. There are apps and iPads and how we master that; maintaining of patient confidentiality; and also knowing that whoever is on the other end, which is HR's challenge, has the right credentials, is AHPRA registered, blah blah. But that is work in place. There is also trying to maintain that human part of that. I guess that is why you still will need people at our end, and the volunteers play an important role in boosting what are limited resources.

The CHAIR — Thank you very much for that.

Ms PATTEN — I just was really struck by the matchmaking program. I just love that process. It was just gorgeous. But I was also really struck by what you said about getting too close. I just wondered if you could tell me what that meant?

Ms BEAUGLEHOLE — Yes, it is because of the sharing opportunities that I have experienced. I am a quiet sort of a person and have been matched with people who tend to match that as well. We can sit and talk for — gosh, most of the experiences I have had have been talk, talk, talk until you nearly need a throat lozenge, and that has been quite amazing. You just really are sharing on quite deep levels sometimes, particularly in the early days of getting to know each other.

The formalities of it all sometimes do get overtaken by friendship. The level of it is still different to going down the street to have a cup of coffee with somebody else. You are in a different situation, of course, but you leave aside all of your hang-ups, if you like, and you are just there sharing in that close and caring manner so that you actually become close. As I say, if you just do not get into anything controversial or anything, my experience has always been to share pretty much from the heart quite often, whether it is your love of craft or what you think of what is coming on TV or the rubbish you wish you could avoid or, in that regard, so-called entertainment, and just all sorts. You tend to interact more closely on a heart level, I guess, for me.

Ms PATTEN — I guess I wanted to know what made you with that woman say, 'I'm too close now; it's time for Ms Smith to take over.'?

Ms BEAUGLEHOLE — That was an interesting one. She is a very vibrant lady, who is very strong in herself. Otherwise she would have faded away long before this under the circumstances of her physical illness, which can only go in one direction. At some time, it could happen — bang! like that — tomorrow, or she might have many, many years. She is a really strong lady to keep going as she does. She is very vibrant, a much more vibrant type of person than I am, so I could easily get drawn into her situation of, ‘Come and try this craft’ and ‘You’ve got to have a go at this craft’, which was really, really special; but in the end I was dragged in and I could not step back. It needed a complete break.

Ms PATTEN — Yes, I understand.

Ms BEAUGLEHOLE — She was not someone just lying in bed, and quiet; she was vibrant and alive, as Lyn is finding still. If Lyn was willing to share, she would say that it has only gone on from strength to strength in that same way, because this lady who has had some horrendous times is really determined to keep going for as long as she can. They have some very interesting Monday nights.

Ms SMITH — We do.

Ms BEAUGLEHOLE — Very interesting, so talk about what you do, just a little bit, because it is special.

Ms SMITH — We often watch *Australian Story* and then have a good covering discussion about it. Those sorts of things, and what has been going on in the week.

Ms PATTEN — It is probably better than *Keeping Up with the Kardashians* or something.

Ms SMITH — Absolutely.

Ms HEENAN — As part of their selection, there is an interview process and referee checks of all volunteers and so forth, and there is a role description, but all volunteers go through the interview process and need to be mature. Somebody might be better for community transport rather than palliative care, and Lyn’s background is 10 years of pastoral care with her Uniting Church, so that spirituality is there. She might be quiet, but you know, she is a very special person.

Ms PATTEN — One more question to you, Ms Heenan. Is there anything that is not money that governments could do to improve the services you provide?

Ms HEENAN — I know we have a strategic plan but with the consortium it is fantastic to have a regional approach for small health services. It gives us greater leverage in what we do through that ability as a collective to achieve greater outcomes for our smaller communities, which we would not have on our own without that partnership. There is funding there, but it is about having a strategic plan. We talked recently about the strategic plan and I said, ‘But it only goes for really two years’, and they said, ‘But that’s the length of our funding’. To have that big picture stuff, that longer picture of where you are going to lead your community, the boards and how that fits with your values would be of greater assistance to us. To have that strategic ability to plan ahead, whether it be four years or a maximum of five, but to have that funding extended a bit more — only two years is not long enough.

Ms PATTEN — Yes, good point.

Ms HEENAN — Otherwise in the rural communities we are quite good at working in partnership to make things work collectively and collaboratively for better outcomes at the end of the day and without extra money, but that is always welcome, which means an extra EFT — but, yes.

Ms PATTEN — It seems to me sometimes that it is just refocusing the money.

Ms HEENAN — And also about that capacity development approach is the training and outreaching further to regional services and out to areas, rather than having it centralised. It is too difficult — the tyranny of distance.

Ms PATTEN — Yes, that is a good point. Thank you.

The CHAIR — Thank you very much, the three of you, for being here today and for your evidence and what you do in the community. We sincerely appreciate it.

Ms HEENAN — Thank you. It was nice to meet you.

Witnesses withdrew.