

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Bendigo — 12 August 2015

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Ms Catherine Kemp, Palliative Care Coordinator, Swan Hill Palliative Care Services, Swan Hill District Health.

The CHAIR — Ms Kemp, thank you very much for joining us this morning. I will shortly make a formal introduction, but I want to take this opportunity to thank you for coming down from Swan Hill to join us today; it is much appreciated. 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 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 a proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website. Ms Kemp, you are the palliative care coordinator for Swan Hill District Health?

Ms KEMP — Yes, that is correct.

The CHAIR — Thank you very much again for being here. We look forward to what you have got to say, and thereafter the committee will have questions.

Ms KEMP — Thank you. Good afternoon. As mentioned, my name is Catherine Kemp. I am a clinical nurse consultant and coordinator for Swan Hill Palliative Care Services, which incorporates the regions of the Rural City of Swan Hill, the Gannawarra shire and the Buloke shire. I am reading from a statement that will address components 1 and 3 of your terms of reference, focusing on the areas of palliative care and change, as that is where I work.

Person-centred care works well in palliative care, assisting clients to discuss and plan their end-of-life care. Advance care planning is incorporated into practice and includes the use of all or a combination of medical power of attorney, refusal of treatment certificate and statement of choices. From the perspective of a rural and regional service provider, communication is the key to ensuring the person can proactively manage their end-of-life care. A client of our service may reside in Manangatang, their GP will be in Robinvale, palliative care in Swan Hill, an oncologist in Bendigo, a neurologist or cardiologist in Melbourne and a local district nursing service that only operates three days a week. The district nursing service, the case management service and the palliative care service will attend a home visit. The person has to travel a minimum of 9 hours for a return trip to Melbourne for specialist treatment. Utilising the advance care planning and the patient planner or diary, of which you have a copy, ensures that all aspects of end-of-life care planning can be in the person's interest, if they choose to use these.

Advance care planning is a person-centred approach that should be commenced well before a person reaches the area of palliative care. All public hospital inpatient and community services within our region are ensuring that staff are trained in the areas of this service provision. However, these documents, specifically the statement of choices and refusal of treatment certificate, require a medical officer's intervention. There are eight hospitals within the Swan Hill community palliative care service region. Only one of these has a medical officer on site for 24 hours. So therefore, even if the inpatient or community services undertake these documents, the person still requires a visit to the GP. There is currently no MBS item for advance care planning for GP clinics, and the process can take two or more visits, so there is a very poor uptake of advance care planning in GP clinics.

Due to our rural and regional location, preferences for end-of-life care are limited, due to geographical reasons. The Manangatang client may have no carer or may have a frail, aged carer who is unable to support them to die at home, even if this is their preference. This is due to a lack of community support, community services. Inpatient palliative care is available at Mildura, Bendigo and Echuca, all requiring travel and accommodation for families and carers. There is one acute bed set aside at Swan Hill District Health, which is an acute-funded bed, so it is therefore limited to short term and is based in an acute clinical care-focused area.

There is currently a community group in Swan Hill titled the Swan Hill and district hospice committee, that commenced due to the end-of-life choices of the two women who founded this committee. They both had a family member die in the Bendigo Hospice, and whilst these were well supported deaths for both the person dying and the families, the extra burden of travel and accommodation was magnified. In the previous seven months this committee has raised over \$94 000 to go towards a hospice and end-of-life care facility in Swan Hill.

The department of health has identified that Swan Hill District Health requires a subacute facility to improve service provision in the local region and reduce the burden of travel and accommodation for families. However, due to a lack of space for this to occur, the funding was not forthcoming. With the relocation of the nursing

home into a new facility, the space is now available, so the hospice committee are hoping that the subacute facility can incorporate their hospice. This point is being raised to demonstrate the community support behind end-of-life choices. They are aware of their ability to access local services, and they want to do so.

Portable telehealth is enabling palliative care patients to liaise with specialists and discuss their end-of-life choices. The VCCU centres — that is a video-link centre — exist within all rural hospitals, and portable telehealth via handheld devices exists and ensures that clients who are unable to leave home can still access that medical care. But if the specialists do not have access or the ability to use these, or if the capacity to obtain a network connection is not available, it is a useless service. Broadband or wireless communication does not immediately spring to mind as an end-of-life choices concern but is very much a factor in our region.

In summation, change that would benefit our rural community includes: enabling an MBS item for GP clinics to undertake advance care planning, to ensure that rural and regional areas are able to access medical support within their local community and to ensure that rural facilities and services can accommodate the choice of the local community as advised by their consumers. Thank you.

The CHAIR — Thanks very much, Ms Kemp, for your presentation. I am very interested in your comments about technology and the role of broadband. Could you talk perhaps more about some of the ways, despite some of the limitations that may exist in the technology, that you are using technology to overcome some of those geographical challenges?

Ms KEMP — Clients can access the palliative care physician at the Bendigo-Loddon Mallee palliative care consultancy service or Dr Becca Chapman within Bendigo Health from home, face to face, using the palliative care iPad. They can have a consultation in-home. Because the patient at Manangatang may have spinal issues and transport is just not a viable option, the need for that medical input into ensuring that their comfort is maintained is invaluable.

The CHAIR — Is that sort of technology also used to access specialist care or specialist consultation in Melbourne? You referred to what would be a 9-hour trip.

Ms KEMP — Yes. The Bendigo-Loddon Mallee region operate on the Polycom system, so we utilise the Polycom system to liaise with Bendigo specialists — not just palliative care, maybe cardiologists or oncologists. Melbourne specialists do not all utilise that, so Skype, which is free and in the public domain, is used quite frequently.

Ms PATTEN — Thank you. I think this is the first time we have heard in our hearings about the really practical use of new technology, so it is encouraging. I really liked your three recommendations. They have been reiterated in other places. One of the issues that some of the other palliative care teams in regional areas that we have heard from have mentioned is medication and concerns about carrying large amounts of medication or leaving caches of large amounts of medication, particularly for regional or remote patients. Is that something that your team has a concern about, that you are aware of?

Ms KEMP — No. We have not encountered that as an issue. We provide a locked box for use in the home. Our patients might live on a farm 80 kilometres from the nearest town. The district nurse is only going to be able to come once or twice a week, so the families themselves are taught how to draw up and administer those medications. They are injectable medications, which people get nervous about, but they are the same strength as the oral medications they were taking when they could take them.

Ms PATTEN — That has not been found to be a concern?

Ms KEMP — It is not been found as a concern for us, no.

Ms SPRINGLE — Following on from Mr O'Donohue's question about the technology, you mentioned network availability being a challenge. I do not expect you to have figures or statistics off the top of your head, but is it common that there would be no network connection? How does that impact?

Ms KEMP — Yes, it is common.

Ms SPRINGLE — Very common?

Ms KEMP — Yes. If you are in an actual town, you will have coverage. If you are on a rural property, you may have some coverage but inadequate coverage to provide a video link. You may be able to phone link in with a medical specialist, but that does not allow that face-to-face connection.

Ms SPRINGLE — How are people overcoming that challenge currently?

Ms KEMP — We are using phone link.

Ms SPRINGLE — That is it?

Ms KEMP — Yes. We are utilising phone link. We can take photographs of physical issues that we want advice on and send them to the specialist, so that he has them to look at during the telephone link.

Ms SPRINGLE — Okay.

Ms KEMP — But in the home environment with video link accessible — and you know it is this big — you just point the camera and he can say lift it, lower it, whatever.

Ms SPRINGLE — And certainly with perhaps ageing patients, are they comfortable with using technology like that?

Ms KEMP — Especially if it is saving them travelling.

Ms SPRINGLE — Okay, and so not having that as an option, how is that impacting on the quality of care?

Ms KEMP — They are refusing to go to appointments. People will not seek that medical advice if it means that they have to travel to get it, when they are already uncomfortable and they are already at a financial disadvantage, because a trip to the specialist may also mean a night's accommodation. You also have to eat. Your frail aged carer may come with you, but you might need to get your family to take a day off work and come as well. So it is a financial disadvantage due to the geographical location.

Ms SPRINGLE — So they will just put up with their pain or whatever the impact of their illness is?

Ms KEMP — Not necessarily. We will try to manage those symptoms as best we can, just without that direct link with the specialist.

Ms SPRINGLE — Okay, thank you.

Mr MELHEM — Thank you, Ms Kemp. In your experience do you think we are meeting community expectation in relation to the choices people have in relation to end of life, particularly in the regions with the distance, and if we are not, can you give us some suggestion of how we could do that?

Ms KEMP — As an example with the home and community services there are some significant cutbacks on those services. It is already difficult to access in a rural environment, not so much regional, so within a town you can access it but remotely it is very difficult to access. With further cutbacks we have found it more difficult to attain personal care, home care support for our rural clients.

Mr MELHEM — Because of the distances are we seeing any cases where people are giving up — for example, basically saying it is too hard and I will just give up on life or just give up because of the distance, because we have not got — —

Ms KEMP — I think that can happen in any environment where a situation is beyond their capacity to control it. I do not think that is necessarily a reflection of the services.

The CHAIR — Ms Kemp, with the sort of catchment that you service and many remote communities or people, as you said, on farms a long way from the nearest town, could you comment on people's preference to have that end-of-life care, particularly towards the end, at home or at another location?

Ms KEMP — The majority of our clients would prefer death to occur at home. They can change their mind as disease progression occurs due to the extent of care that they require, not anticipating or understanding quite clearly how impacting 24-hour care is on families. So palliative care offers to support them with their choice, so

long as it remains safe for them and their carers and that symptoms are managed. We do not promise to keep people at home, but we do offer to support them so long as they are safe and comfortable.

The CHAIR — How many people who perhaps express that wish end up passing away at home or how many would end up in a — —

Ms KEMP — We have about 20 per cent of our clients who die at home. There are others who initially would like to die at home but who due to circumstance or change of mind die elsewhere.

The CHAIR — Is that mainly elderly?

Ms KEMP — Elderly with a frail aged carer or with no carer.

Ms PATTEN — Speaking of carers, some of the other people we have spoken to have spoken about how for a carer to assist someone to have that choice of a good death at home they do not necessarily need to be a nurse. They do not need to be a medical practitioner. It could be someone who is a home carer.

Ms KEMP — Exactly, they are.

Ms PATTEN — They can provide that assistance to the elderly carer or a carer.

Ms KEMP — Yes.

Ms PATTEN — Do you have those home carers within your group?

Ms KEMP — Do you mean an external home carer from a support service?

Ms PATTEN — Yes.

Ms KEMP — Not a great deal, no. We can access carers respite, but that might be 2 hours a week and that is not going to provide a great deal of relief. It does enable them to get down the street, pay some bills, get some shopping and go for a coffee; but it is not going to relieve that burden of care greatly.

Ms PATTEN — No, and so in some cases it is just about caring. It is not necessarily about medication. It is just having an able — —

Ms KEMP — A person.

Ms PATTEN — A person, thank you. Can I just say one more thing? We have heard about your book around the state.

Ms KEMP — Good.

Ms PATTEN — Congratulations. I have just had a flick through. It is fantastic and it has been complimented in other regions.

Mr MELHEM — It is a great book. I agree it is a really good book. Do we adequately provide for paediatric and youth palliative care in the regions?

Ms KEMP — We do have the Victorian paediatric palliative care service, which essentially covers the state. If the child and family want to return home to our region, which is their home, to die, then, yes, we will be supported by that Victorian paediatric palliative care service.

The CHAIR — Can I just ask a further question about respite, because that is obviously an issue. We heard from the previous witness as well — and from other locations — about the challenges of accessing respite. Do you want to talk a bit further, to add to what you said before. You mentioned 2 hours.

Ms KEMP — Yes, which sounds inadequate, but can also be a relief. The access of in-home respite can be difficult if you live remotely, because the person providing the respite has to use their own vehicle. If we advise them that the person lives 80 kilometres from Swan Hill — that is, a 160-kilometre round-trip — they may choose not to take up the carer respite for that person. If we can access a case management service, which is

very difficult, they will be able to broker a carer service; but again it is the cost of transport that takes up the majority of the funding.

The CHAIR — From whom would you access a case management service?

Ms KEMP — To access a case management service you have to go through the Aged Care Assessment Service to be approved for a case manager. If they are under the age of 65, we first go through the department of health to attain permission for that. Then they go on to the waiting list. You can be placed as a high priority on the waiting list, but the waiting period may still be 12 to 18 months.

The CHAIR — Does that waiting list depend on the ability to access services in a particular region?

Ms KEMP — There are a finite number of case management services available, and they are all full all the time. You are essentially waiting for somebody to move into aged care or die for another person to get a position.

The CHAIR — Thank you very much, Ms Kemp, and thanks again for coming down from Swan Hill. It is much appreciated.

Witness withdrew.