

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Bendigo — 12 August, 2015

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Ms Melissa Weaver, Care Manager, and

Ms Marlene Connaughton, Manager of Integrated Services, Strath-Haven Community.

The CHAIR — I will reopen the Legislative Council’s legal and social issues committee’s public hearing in relation to the inquiry into end-of-life choices. Ms Melissa Weaver and Ms Marlene Connaughton from Strath-Haven Community, we thank you very much for joining us today and look forward to hearing what you have to say to us. Before we get underway I will caution that all evidence taken in 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 and 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. We have allowed about half an hour for our session today, so I invite you to make some opening comments and remarks, and thereafter the committee will have questions. Thank you again for being with us today. It is much appreciated.

Ms CONNAUGHTON — I am Marlene Connaughton and I am the manager of the Strath-Haven nursing home. I have actually been at Strath-Haven for only six months, but previously I worked for Bendigo Health. I have had over 40 years experience in aged care, so all of my nursing career has basically been in aged care. Melissa has had 25 years experience in aged care. In respect to end-of-life pathways within aged care, we believe within our aged care we do have some end-of-life pathways. We do use them within our service and we believe that we use them quite well. But in saying that, there are times when there are sticking points for them not to work as well as they should.

One of our main areas is an end-of-life plan for people. When we admit people it is often a traumatic time for them, being admitted to an aged-care facility in the first place. Families are going through a grieving process as well, and the person themselves is traumatised by having to come into an aged-care facility, which I think we all would be, even though we do a good job with it. Then we actually ask them to do an end-of-life pathway. Already they are stressed, having just got there, and then we say to them, ‘Can you just fill out these four pages of information for us?’. So that is very difficult for us to get from families. We often take about three or four months to get that information back from families. Some families are good, of course, but others are not as good in that area. I suppose an example is that we admitted somebody two weeks ago —

Ms WEAVER — Can I interrupt you for just a moment? The idea of our organisation or the residential care organisations is that we promote ageing in place. That means that once they come into residential care, we will look after them until the end. So it is vitally important that we have the document that Marlene is talking about, enabling us to carry out their wishes.

Ms CONNAUGHTON — We had a gentleman admitted two weeks ago. He became unwell on Monday, we called his GP, and the first thing his GP said to me was, ‘Do you have an end-of-life pathway for this gentleman?’ and I said ‘No, he has only been here two weeks and the family have not done one’. For me, that GP should have had that conversation with those people before they came into the aged-care facility. So I suppose that is one of the biggest sticking areas for us.

Melissa and I had a talk before we came here. In the regional areas, having access to GPs is a difficult one for us. We do not have a locum service in the regional areas. A lot of services work only 9 till 5. They do not have after-hours services in the regional areas, which makes it difficult for us to access GPs. I suppose for us the areas we have come across over the years is the education of GPs, knowing the right drugs to use, how to talk to families and when to talk to families. Those types of things are sometimes difficult. We often have the conversation with the GP before the GP speaks to the family, and they want us to know what they would like us to say to the family and that type of thing.

Ms WEAVER — We do have some GPs who will come in and do a clinic and see residents as we request, but a lot of our residents who come in choose to keep their own GPs, who are not keen on visiting our facility. For some reason they have developed a culture that visiting aged-care and residential services is really time consuming and difficult for them to manage in the time that they have out of the clinics, and in some aspects it is not financially rewarding. It puts us in a difficult situation with ongoing care and managing palliative care if we do not have that support from the GP.

The other issue that we do have, too, is attracting qualified staff to facilities like ours who have been through the right training to be able to support residential care and end-of-life wishes and palliative care. I went to a forum a while ago where they said that aged care is not sexy and is probably not high on the agenda compared to A & E

and midwifery. Aged care is probably lacking in the sense that we do need dynamic, well-educated staff to support what we are talking about today.

Ms CONNAUGHTON — In my experience I would say that 10 years ago if I advertised a position for an enrolled nurse I would get something like 40 or 50 applicants, but we advertised about a month ago and we got 4 applicants. It is wonderful that the enrolled nurses are getting those higher skills, but they do not want to come and work with those higher skills in the aged-care sector, they wanted to go and work in the EDs and all of those areas.

Ms WEAVER — Aged care really is hard work and it takes a very well-organised and educated person to be able to maintain a position in aged care. If you look at the changeover of employment in any of the aged-care facilities, you see that people actually get burnt out because there is such a workload involved. To be able to manage well what we are talking about today we need to have the people in those roles who are educated to be able to support people.

Ms CONNAUGHTON — As well as enrolled nurses, registered nurses are hard to get into aged care. You can go and work in the acute setting, which is wonderful. There are registered nurses in my facility who have a 1:30 or a 1:40 ratio, which is a big difference in workload. You are often the only clinician who is there, making the decisions. You do not have a support person, although our registered nurse is on with both Melissa and me there, but I am often away. It is not like it is in an acute hospital. So that is the difficulty in aged care in those areas.

Our personal carers do a wonderful job, as Melissa said, but they probably have not had the training to have the higher skills to do the clinical assessment of people who are end of life or to identify when someone is approaching end of life.

Ms WEAVER — As part of our organisation, and I cannot speak for everybody, but we put our careworkers, our ENs and our registered nurses through a palliative care program. So within Uniting AgeWell, our group of workers are all on the same page in what we are trying to achieve in supporting end of life, so that is for our organisation. I cannot speak for other organisations.

Ms CONNAUGHTON — One of the other areas we briefly talked about between ourselves was access to medication, particularly after hours. We actually had a medication advisory committee meeting this morning at our home, and we are going to make an application for a drugs and poisons licence to be able to keep after-hours medications. At the moment if somebody becomes unwell overnight, we have a contract with a pharmacist who can be called to come and do that. Even for somebody who might have a urinary tract infection and is unwell, we have to wait until the next morning to get an antibiotic for them to start. By having an increased system for drugs and poisons, we can actually do that more quickly and things like that. However, there are about this many pages to fill out, and there are rules and regulations we have to meet to do that. I think that probably stops a lot of people from doing it. It is not the cost, because it is not that expensive to do, but there are a lot of rules and regulations associated with it, which I think puts people off. I think that kind of a process, being able to access those medications easily for people at end of life, would be good as well.

Ms WEAVER — If we feel that we need medications and we cannot get medications, because maybe the GP has not ordered them or they have not been in to review, and somebody is very ill, we need to send them up to the emergency department at Bendigo Health. We sent somebody up yesterday, and they said, ‘You’ll be going knowing that you will be sitting behind 10 other ambulances. That is probably an issue as well. We could not get the medication we needed for this lady. She chose, and her family chose, to go up to the ED to be reviewed, and in order to get medications that is probably a process that we have been through, because we have not been able to get drugs to support our residents.

Ms CONNAUGHTON — In saying that, one of the better things that has happened is Residential In Reach. Have you heard about that program? It is in Bendigo. I think it is within Victoria. It is a group of highly experienced clinical nurses that is run from the acute campus, who come out to aged-care services and support aged-care services. That has been such a wonderful support to us in our aged-care areas. I suppose it is not really end of life, but they do support us with end-of-life things as well. If somebody has a fall and we are querying a fracture, what would happen if they went to the emergency department? They would sit on a trolley for 3 hours waiting for someone to see them, then they would go and have an X-ray and then they would come back and say, no, they have not got a fracture. We can ring Residential In Reach, they can get an X-ray form so

the ambulance takes them straight to the X-ray department. If there is no fracture, they bring them straight back to our home rather than them having to sit on a trolley. Also they support us if we cannot get access to a GP for pain management or for palliation.

Ms WEAVER — For anyone who has been in hospital, post discharge Residential In Reach will come out and do a follow-up visit. It is just great.

Ms CONNAUGHTON — That is a really great program supporting aged care in Victoria.

Ms PATTEN — What was it called again?

Ms WEAVER — Residential In Reach.

The CHAIR — Who funds that program?

Ms CONNAUGHTON — I think it is the state government. It is excellent for us when we cannot get access to GPs and things like that. They do work after hours — they work until 9 o'clock at night.

Another area we talked about was equipment — mainly things like access to syringe drivers. I am not sure if you know what they are — they give people less pain. We actually only have one in our whole facility for 94 residents. We have been lucky that we have not needed two at once.

Ms WEAVER — We can hire from other services around Bendigo, which we have done before when we have needed two or three. We have 94 beds at our facility, so when we do need to get equipment we can hire it, obviously at a cost to us. Having that ready to go would be really comforting not only for us but for our staff and our GPs as well.

Ms CONNAUGHTON — And I suppose there is the cost of facilities to have those. Previously, not when I have been at Strath-Haven, but when I was part of Bendigo Health, which is the public sector, there seemed to be a bit more equipment in those areas. We have been contacted by other private places, and we cleaned out our syringe drivers when they have had two or three people as well, so having been able to have access to that equipment has been important. Palliative care can also support us if we ring them and ask them. They will support us with equipment as well. The community palliative team can come in and support us in those areas.

Ms WEAVER — One of the other things that is a real benefit to our organisation is the end-of-life care plan. I am not sure if other organisations use that, but given the different skills amongst our workers, it is a common tool that all workers can use to ensure that somebody is comfortable at the end stages of life, so that is probably worth noting as well.

The CHAIR — Great. Is there anything else you would like to add before we go to questions?

Ms WEAVER — No, that is it.

The CHAIR — Thank you, ladies, for those opening statements. If I could just ask you about the end-of-life plan, you talked about GPs saying, 'Where's the end-of-life plan?'. That possibly could have been something the GP discussed with the patient. How common is it that someone has an end-of-life plan already in place before they come to your facility?

Ms CONNAUGHTON — Not very common.

Ms WEAVER — Not very common. In the last 12 months, I have had one come in who has already had an organised care plan, and her daughter is a nurse. That care plan will be asked for. If we transfer somebody to the ED department for whatever reason, the first thing they will ask for is the care plan.

Ms CONNAUGHTON — The advance care plan.

Ms WEAVER — The advance care plan. We are forever chasing them and having that difficult conversation. I rang up families for over six months trying to chase that.

The CHAIR — Right. So in your facility most of the residents would have one completed?

Ms CONNAUGHTON — We have about 60 per cent who have one.

Ms PATTEN — Just following on from that question — —.

Ms WEAVER — Can I just go back to that question? Sorry. In some senses too, it is a valuable tool, but when that tool actually needs to be implemented, those who have made the earlier decision can actually change their mind about it.

The CHAIR — Sure. Does that happen quite regularly? We have heard evidence before that things can change, but at least it is a basis from which to work, I suppose.

Ms WEAVER — I have made the correlation before — I am a midwife as well — it is bit like your birth plan. As soon as you walk into the hospital the birth plan sort of goes out the window. I am not saying that it is what happens in every case, but when families are actually confronted with making that decision, you know, ‘We have made this decision. Are you happy to go with that?’. ‘Actually, no, we are not’.

Ms CONNAUGHTON — It is just that last-minute decision for some people. It is not a huge, common thing. Most people are ready by the time that comes, because we have had that conversation with them and we have had the case conference with the GP previously. Just this morning we had a case conference with a family and with the GP.

Ms WEAVER — We have had three prior to this — a case conference with this family — and still the attitude is that there are four children involved, and we are still case conferencing end of life. Sorry, Fiona.

Ms PATTEN — No, that just struck me. I have a question about that. So when there is a change of mind, is it your client or their family who is the one who changes their mind more often?

Ms WEAVER — In 90 per cent of cases it is the family.

Ms PATTEN — It is the family. So it might be that your client has gone through this plan with you and the family overrules that?

Ms WEAVER — They overrule that plan. Yes.

Ms PATTEN — One of our previous witnesses mentioned legislating so that our end-of-life plans or advance care planning is more rock solid.

Ms WEAVER — Yes, do it with your will.

Ms CONNAUGHTON — Yes, make it a legal document. We talked about that.

Ms WEAVER — Yes.

Ms PATTEN — Sort of like the refusal of treatment?

Ms WEAVER — Yes. Similar to that, especially if anyone has a palliative or terminal diagnosis. At the end of the day that decision is probably taken from them, but how do you want to manage that?

Ms PATTEN — Particularly a parent, so families can overrule or override it.

Ms CONNAUGHTON — Yes.

Ms WEAVER — Yes.

Ms CONNAUGHTON — The biggest conflict probably is between families as well. One wants dad to go, one wants them to keep going. One said, ‘He is not swallowing very well’, and they said, ‘Let’s not give him any medications anymore’, and the other one said, ‘No’, wanting him to have his medications. We try to explain to them how difficult it is to get them in there.

Ms WEAVER — I guess it is identifying that particular point — you know, where is our quality of life? At what point do we decide that we will stop medications and that we will put a syringe driver in? At what point do

we make you comfortable? That is the grey area. Even the doctors will ask at what point you draw the line in the sand, and that was the conversation that I had today.

Ms SPRINGLE — Thank you. It was very insightful testimony. I refer to your comment just now about doing the advance care plan with your will. We have heard at other hearings other testimony saying that that would be problematic, because the care plan would be with a will, which medical staff do not necessarily have access to in, say, emergency situations or what have you. Do you think that would be an issue?

Mr CONNAUGHTON — We currently now get copies of legal documents like an enduring medical power of attorney, and we keep them there — and powers of attorney and those things. I do not think if we had a copy of it that it would be — —

Ms SPRINGLE — But is it up to the patient themselves to instigate that? What are the logistics around that?

Ms CONNAUGHTON — We ask for that. I think that as part of our admission process we ask for that to cover ourselves. Who makes the decisions? Who pays the bills? — all those types of things. I think as part of their care and the case conference we have with them six weeks after admission, making sure we have that documentation and ticking it off would be good.

Ms SPRINGLE — So in an aged-care context it would work, but perhaps in another context there might be problems with it?

Ms CONNAUGHTON — Yes.

Ms SPRINGLE — I am just trying to get my head around the differences in logistics.

Mr WEAVER — I guess when we sit down and we make decisions about where our money is going to go and our property is going to go after we die, we probably need to have a conversation before that about how we want to manage — —

Ms SPRINGLE — Certainly there was no doubt around the need for it; it was just about logistically where it sits and who has access to it, and that seemed to be more of an issue for some practitioners.

Ms WEAVER — We could definitely have a copy of that, and a copy could stay with the solicitor and part of our entry process is that you need to have that document.

Ms CONNAUGHTON — But you are right. In the context of residential services it is probably easier for us to manage, because we gather those things, but in the context of if you are going into hospital and things like that in those areas — —

Mr MELHEM — On that issue, would you then look at making it mandatory that as part of the admission process a person must have an advance care plan, or are you saying it must be offered?

Ms WEAVER — Like Marlene said earlier, it is a difficult transition going from maybe a home environment to coming into aged care. It is really tricky for a lot of people to lose their independence, so they are focusing around perhaps changing GPs, perhaps a new environment to be living in surrounded by new people and, 'By the way, how do you want to die?'. It is very confronting coming in, and that is why we try to be very gentle about doing it, because obviously this is the last stop.

Mr MELHEM — Just on that, have you got any figures on what is the average stay of a person in an aged-care facility like yours? I am talking about the admitted and then leave-this-world type.

Ms CONNAUGHTON — I do not have any for our facility, but my understanding from a previous life is that that length of stay in aged care is reducing gradually. I have not got the exact figures. I have had my life in aged care. When I first came into it we had people who were there for eight or nine years. Now I think about 18 months is probably the longest time, so it has reduced over that time. I have not got the exact figures, but anecdotally I have noticed that, and it has been spoken about previously.

I think that it is going to make it even more difficult now, with the changes for more people living in the community longer. Because there are more supports in the community, people are going to want to stay home,

so when we get them they are going to have comorbidities. Probably we are going to turn into more of a palliation rather than an aged-care home. If people want to stay home, that is their choice — research has shown that. We are bracing for that to happen in the next two or three years, once there is a stronger community package and more support at home for us to be the next stop is more — We do have ageing in place, so people do come in who are not too bad. We have a lot of people who are quite well and might be there for two or three years, but that is getting less and less. When they are coming in, they are coming in weaker and with more comorbidity, so the length of stay will be much shorter.

Mr MELHEM — That is the other point about why having a plan is important. At the other extreme, and I am talking from personal experience, my mother-in-law has been in aged care for four years. She has dementia, she cannot walk and she cannot do anything, but she is happy, and hopefully she could be there for another 10 years, hence the question about the two categories — 18 months, 6 months? You need to have a plan for individual circumstances.

Ms CONNAUGHTON — Yes.

Ms PATTEN — I have a couple of questions, but that was a really interesting point that you made there. Would you see that then your services would also be incorporating respite? I think your services already do respite.

Ms WEAVER — We do respite now. Yes.

Ms CONNAUGHTON — Yes.

Ms PATTEN — We have heard at previous times that that has been something really lacking in the community.

Ms WEAVER — We have a respite bed.

Ms PATTEN — You have one?

Ms WEAVER — No, we have two. We have one in the general area, and we have one in our dementia wing, and they are full all the time — booked up for over 12 months.

Ms CONNAUGHTON — In fact we are fully booked in our respite until February for both of our beds. The other program that we run is with our national respite for carers program. We run a weekend respite program as well, so every fortnight for Friday, Saturday and Sunday we have a house, and we have about six or seven residents stay in that house for the weekend. It is like a little holiday for them, and their families get a break. We run one of those as part of our community program.

Ms PATTEN — That is lovely.

Ms SPRINGLE — You mentioned that you have problems getting GPs to come into the facility. What is the impact of that?

Ms WEAVER — The impact of that is that none of the residents gets the care that they probably need at that time. We do have a GP who does a regular clinic, and he will see a lot of our residents. If residents come into care who have a GP who will not visit, then quite often this GP will pick them up. It is a great model of health in the sense that we can do a list for the doctor to review, and he can review anything from 5 to 20 people on a clinic day. That is a wonderful service to have in place because, as you are probably aware, we have had an influenza virus at our facility, and because of that GP who visits, all of his residents have been covered. They have had swabs done and they have been covered with antibiotics and then they have been reviewed. Those residents who do not have a GP who is on board with our philosophy can go a long time without being seen. The effect of that is that, if they have comorbidities, as Marlene said, and the burden of infection, that can create behaviours and create poor outcomes for their own wellbeing. They will become dehydrated. They will become very sick.

Ms CONNAUGHTON — I suppose the main area is that when GPs do not come to visit and if they need some urgent care, we have to send them to the emergency department. We try to reduce that as much as we can. Emergency departments are good if you are really sick, but sometimes they are not drastically ill, but they need

to go and get some medical care, so that is traumatic for them as well, so it is difficult to do that. An example is that we have a lady who has been unwell for weeks, and it has been difficult to get a GP to come in. The family spat the dummy yesterday and said, 'We want her to go up to the emergency department and see what they can do'. The ambulance came and told us that they did not want to take her, and she said 'I want to go'. They said, 'But there are about 10 ambulances waiting there, you will be sitting on a trolley forever', and she said, 'I still want to go', so they took her up there. That is the issue when we do not get the GPs.

We do not have a locum service. Each resident gets to choose their own GP who comes into residential aged care. They may have had that GP all their life, but when they come into the aged-care service, the GP does not want to pick them up. That is when we are really lucky that we do have a GP who will support us in that way if he does not already have too many. That is probably one of the biggest issues in there.

Ms WEAVER — I think if there were an incentive for GPs — and I have chatted with a number of GPs because I talk with them every day — to take up a clinic in residential care — I do not know what the incentive would be, but if they could do a regular visit twice a week to aged-care facilities, there would be reduced presentations in your ED and you would also have happier clients, happier families and a happier work staff.

Ms CONNAUGHTON — It is more of a wellness model than a medical model.

Ms SPRINGLE — When you talk about there being a financial disincentive, what do you mean by that?

Ms CONNAUGHTON — I am not an expert in this area now, but a few moons ago, before they brought in that you have to have your own GP, we had a GP who worked for the hospital — it was the Anne Caudle in those days — and he looked after all the residents. There were two who looked after them, but then they brought in everybody having their own GP. He picked up most of the residents and took up a practice of his own. He was not hired by the service any longer. He was working away beautifully with that, but then what happened is, because he did not have a practice and was not seeing people who were nought to five or were teenagers, he got a lesser rebate back from the government. I am not an expert in this area, but this is what I was told. He ended up leaving because a GP who had a practice that saw a cohort of different people was getting, I do not know, a \$20 rebate and he was getting a \$10 rebate.

Ms SPRINGLE — He could have made more money elsewhere.

Ms CONNAUGHTON — I am not sure if that is still the case now, it is not my area of expertise, but that was a big issue a few years ago. I suppose it is about looking at that. It is a time thing with GPs. When you think about it, if you come and see one resident in our home, it will probably take you an hour by the time you drive there, park, get to the facility, see the person, have a chat to them and then get back to your practice. In that hour they could have seen four or five people in their practice.

Ms WEAVER — Whereas if we have a clinic in house, he can see six or eight people in an hour.

Ms SPRINGLE — Yes. Thank you.

Ms PATTEN — It was interesting when you are talking about the medication, and obviously this follows on from the discussion about GPs and emergency departments. When we have been talking to some of the community palliative sector, they have spoken about locked boxes in the house, syringe drivers and all the equipment. There has never been a conversation about not being able to access that. Why is it different if someone is receiving palliative care at home versus in aged care?

Ms CONNAUGHTON — We have to meet the requirements of the drugs and poisons legislation. Under that we have to have a safe that is bolted to the wall.

Ms WEAVER — We have a medication policy where only certain staff can access that. Probably in the community — I do not know, ignorance is bliss — they do not really have an understanding of what an S8 drug is and the impact of that. We need to be accountable for S8 medications in a facility like ours.

Ms PATTEN — So when a patient — —

Ms CONNAUGHTON — When they are a resident, like a person at home, they will be accountable for their own medications, whereas we are accountable in the aged-care service.

Ms PATTEN — I see.

Ms CONNAUGHTON — We have to meet regulations and legislative requirements under the drugs and poisons act.

Ms PATTEN — Which is why you go through the paperwork to do that.

Ms CONNAUGHTON — That is right.

The CHAIR — Ms Weaver and Ms Connaughton, thank you so much for your time today, for your evidence and for your answers to questions.

Ms WEAVER — Thank you.

Witnesses withdrew.