

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Shepparton — 13 August 2015

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Ms Carmel Smith, Executive Manager, and

Dr John Hetherington, President, Committee of Management, Goulburn Valley Hospice Care Service.

The CHAIR — I would like to welcome Ms Carmel Smith, the executive manager, and Dr John Hetherington, the president of the committee of management of the Goulburn Valley Hospice Care Service. I thank them both very much for being with us this morning. I caution them 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 a proof version of the transcript within the next week. The transcript will ultimately be made public and posted on the committee's website. We have allowed half an hour for our session this morning, so I invite you both to make an opening statement, and thereafter the committee will have questions for you.

Dr HETHERINGTON — Thank you, members of the committee, for this opportunity to explain who we are and what we do. I thought we would start off by me introducing myself and the service, and then I will ask Carmel to describe what the service actually does. I was, in a previous life, a registered medical practitioner. I spent 40 years as an obstetrician and gynaecologist, and I am the voluntary president of a voluntary committee of management which runs Goulburn Valley Hospice Care.

The service is an autonomous, freestanding organisation. We had a grassroots origin 25 years ago — well, we have been going for 26 years now, so 27 years ago a grassroots group of people realised that there was a need for palliative care in this area. Too many patients were coming to the end of their treatable disease in hospital and basically being sent home to die in the arms of their relatives. This was not appropriate, so a small group got together and it gradually increased its size and its abilities, and we are now at a situation where we have about 60 per cent of our funding from the government and 40 per cent from fundraising, public donations and public subscriptions. So we regard ourselves as a thoroughly grassroots community organisation.

Because of our two funding streams, we are very unusual for any sort of health service in that we are sufficiently funded to do what we want to do, and this is a remarkable situation to find ourselves in. It does allow us to be proactive. Our committee of management we regard as being the pathway between the community and the service. Obviously in our social lives and professional lives we get spoken to — matters pertaining to palliative care, to our service, get mentioned to us — and we can take those ideas into the service. Conversely, what the service is doing, providing palliative care, it is up to the committee of management to be part of the propagation of that information into the community.

We have six nurses in our employ, and Carmel is the executive manager; she is also a nurse. Carmel will introduce herself in due course. We also have a coordinator of volunteers, because we have volunteers acting in several different modes. We have what we call patient volunteers, who are trained members of the community who are able, after training and with supervision, to go into the home and help the family and help the patient in just about any legal way you can think of. That is a very demanding job, but every time one of those volunteers spends an hour with a family, that is an hour that we have got of nurses pay instead.

The voluntary aspect of our service is huge. We have about 110 known regular volunteers who work in our op shop, which is extremely profitable, who work on the committee of management and who work as fundraisers. We have a Friends of Hospice fundraising organisation. We have bicycle rides to raise money, and we have car rallies to raise money. It is a very extensive organisation, also a very close-knit organisation, where everybody in it is striving just for one thing — and that is, to provide the very best of palliative care at the bedside in the patient's home. I think perhaps I can stop there and hand over to Carmel to explain to you a little bit about how you go about it.

Ms SMITH — Thanks for inviting us; it is a privilege to be here. My background is that I am an oncology nurse of 20 years, and I moved to the dark side 12 years ago to take over the management of Goulburn Valley hospice care. I have never regretted the move, and it has been a wonderful move to community palliative care. I think one of the strengths of our service is that we are a stand-alone service — we are able to dictate and do what we want to do out in the community, and we do it very well. We have an 85 per cent home death rate against a state average of 21, so we are actually doing something very good out there, and I still believe we are one of the few services now that still do our own 24-hour on call.

So after hours when patients and families ring, or on weekends, it is one of the nurses they know who takes that call. The beauty of doing that is that because you know the family unit so well, and we all work very closely with all of our patients, you know if it is carer fatigue and — we have had children looking after parents who

have psychiatric problems — you can pick the triggers and you know the family so well. So often we can avert a hospital admission by being able to go out and do a visit as needed overnight or on a weekend. I believe that is one of the main reasons that our patients are able to stay at home to die at home in the care of their family, and I think that we do that very well.

We are very proactive in planning that end-of-life care, so we have the drugs in place weeks before they are needed, we have the orders in place and we have very strong support in our community from our GPs. That enables us to do that. But I work closely with the other NGOs in Melbourne, the bigger services, and I know one of the biggest issues they have that does not allow patients to die at home is that their GP will not prescribe the drugs that we need to keep the patient comfortable after hours — if they cannot do that and if the doctor will not sign the death certificate — they are all things that we work on with the family very closely in the weeks leading up to the death of the patient.

People do not realise, but we do actually discharge patients from palliative care not to heaven. They actually get discharged when they are well, and that tends to be more our non-malignant palliative cares, and we are getting more and more of them on the books now. They will often be patients who will come in with an exacerbation of their COPD or who are in heart failure; they will be unwell. We will get involved and support them.

Mrs PEULICH — Sorry, what is COPD?

Ms SMITH — Sorry, lungs, airways — chronic obstructive pulmonary disease. We will go in, get involved with them for a little while, until things settle down. They will bounce back, and then we will discharge them, but they always have our mobile number, so when they deteriorate again, they know us, they are comfortable with us and they will ring us to come back. Anyone can refer to the service. We have only had one patient come in. It was as if he had won Tattsлото; he had been wanting to come on our books for years, which was fairly funny. He was fantastic. He died beautifully at home with his family caring for him. He was just so excited to be referred to us. He finally got a disease that was going to kill him! It is funny; you will get patients walk in the front door and refer themselves.

I was thinking about some of the stuff I have been listening to over the morning. One of the big things, I think, that has to be proved is community appreciation of end-of-life care. Last week Dying to Know Day was on, so we had a stand out at Big W at one of our big shopping precincts. We had information about end-of-life care, advance care planning and the process of dying. It was just so funny. There are two entrances to this shopping centre. People would come and see us, and they would walk right around outside in the rain and come in the other end so they did not have to deal with it. That is, I think, still a big thing. I think people want us there when the time comes and they want to talk about it if they need us — —

The CHAIR — We know the feeling!

Ms SMITH — Yes! But they do not want to have to talk about it then and there. That was very interesting. We did not have a lot of people coming up to our stand and wanting information about death and how people might die.

We are very lucky that we have had over the years — because we have been here so long — a great relationship with Goulburn Valley Health and with Shepparton Private Hospital. Up until this new innovation with the palliative beds coming on — and this is all very new for all of us — our service agreement credentials all of our nurses to actually come into the hospital, see our patients while they are in there, write in their notes, have discussions with the doctors and that. That allows great continuity of care with our families and our carers, and it has worked with us, as she said, for many years, so it is wonderful that she has been able to follow through her consultancy to come here and work now because it gives a lovely balance between her and us, and she knows all our patients.

We have a wonderful IT program for our patients' histories that Goulburn Valley Health has access to. So if one of our patients is coming in, they are able to get on and look up in real time what is going on with our patients. That has been fantastic in the management of some of our patients. All of that we have set up to try and stop the patients from having to be asked the same questions over and over again. Our patients know that they are dying; they do not need to have it addressed with a doctor in casualty again in the medical ward and then with their GP. It is just that if we are all on the same page and we all know that we have had that discussion, it does make their end-of-life care a lot easier.

We do a lot of education, especially in aged care, in the community to try to upskill our generalist nurses, and that has really proven well in aged care, especially in that we now have many more people dying in aged care who we might just be consulting at the end of their life care and they are not ending up in cas in here and dying on a trolley, which is not good for them or their families.

A lot of research has been happening in the last few years around carer burden and carer fatigue. We have just appointed a family support worker, whose background is psych nursing, who has a passion for end-of-life care. She is now doing assessments on our carers, not when we first admit them but as they sort of get used to it. Mel will go in and do a session with the carer just to see what their needs are, because they are on call 24 hours a day, 7 days a week; we are in 1 hour a day, if that. So it is all about giving them the strategies they need to do it. Also, if everything goes belly up and the patient wishes to die at home but it just cannot happen, to support the carer through that, to say they are not letting their loved one down. We do work really closely with our carers and our families that are looking after people at the end of life. They do an amazing job out in the home, and they do become mini-professionals in the care they give. It always amuses me that in our disability homes the workers cannot give sub-cut injections, but we can teach a mother, a father, a brother or a sister to do it in the home.

We probably have about 120 to 150 deaths a year, and we cover the city of Greater Shepparton, so we have about a 2,500 square kilometre area that we travel within. The nurses are fantastic. Some of them have got postgraduate qualifications. Our two young ones are working towards that at the moment. I see palliative care as a very specialised area of medicine and nursing, and I think sometimes in the past we have sort of thought, 'Oh, look, anyone can do palliative care', but I do not believe that. I have seen doctors have bad discussions and not do it well, and that is often where we are brought in. I know certainly Vin has called us in many times to speak to people we are not even involved with just because we are comfortable having those discussions with family. If they are struggling, Vin will offer to ring us to go up to the ICU to initiate that discussion and have those talks.

We are really lucky here that we have the medical students over the road. They do their training here. They come out on the road with us in fifth year, and that is fantastic. We make sure we take them to the really bad ones — the ones who live with 50 cats and have dirt floors — just so they have an understanding that a person's home is their castle and they can die in their place of choice, even if people think that their living conditions are not up to standard. They are their living conditions. We have people who have no carers, such as our alcoholic boys with oesophageal cancers and that, who die on their own at home, but that is where they want to be and that is where they want to die. It works beautifully. People rally; neighbours rally. It is a great service, and I think it is wonderful that we are owned by the community and the community supports us to do what we have got to do. A lot of the time people do not want to be referred to us, but once we get in and they get to know us we do really well.

We have our Aboriginal community coming. I have asked Dean to come this afternoon. A few years ago Rumbalara in the Aboriginal community got the funding to build an aged-care facility in Shepparton. It is a fantastic facility. We have a palliative care room on the end of that, and it has a smoking area out the back and everything. That is going really well. The staff there now are getting better at end-of-life care with our education and our support, and often now they will just need to ring us for management of a symptom that is not going well. They have got their own amazing belief systems. Some of them want to die at home, and some of them do not — the same as any of us. Our job is to support them in their choice of place of death. So that is what we do.

The CHAIR — Thank you both for being here this morning and for giving us more information about the amazing work you do. As Ms Springle said earlier, when we were in Warrnambool we were told that you are the leaders and a model to be emulated, if possible, so it is great to hear firsthand what you are doing.

Ms SMITH — I wondered where you got that from!

The CHAIR — Some of those statistics you referred to — the number of volunteers, the 85 per cent home death rate — are really quite remarkable compared to other places. Clearly you are doing an amazing amount of work in the community. Ms Smith, you have referred to the family support worker you have employed, and that sounds fantastic. What is access to respite services like here in Greater Shepparton?

Ms SMITH — We are really lucky. It is a problem, and it is a problem right across the sector to give families a break. Five years ago one of the groups in Shepparton did a fundraiser, and they wanted it to go to

something specific, so what we did years ago was purchase an aged-care bed in one of the facilities in Shepparton. We have trained up the team that looks after those patients around palliative care. It is one way, but that is only for the over-65s. We have access to that bed whenever we need it. It is fantastic for the older people, if family are going on a holiday, just to give the wife or the husband a week's break. The team works really well, and we are still in and out of the facility while they are in there. They do end-of-life care there. If the family just cannot manage it, and if the person is able to, they will stay there for their end-of-life care.

The under-65s are a problem, and I think it is a problem right across the state. We do access for some of our brain tumours now. Caritas Christi has a program for the younger people, because they tend to be chronic illnesses, and they tend to be very long-term care for the family that is looking after them. It is really awful when you have to put somebody who is young — in their 40s or 50s — into an aged-care facility just so the family can get a rest. We use our community fundraising money to cover the cost of respite. We are really lucky that we have access to that and the op shop money so it is not a burden on families financially.

Tatura hospital, which is an annex of Goulburn Valley Health, does fantastic palliative care, and often that will be an option for a younger patient. We will put them in there for a couple of weeks under one of the GPs over there who has a graduate diploma in palliative care, and she is fantastic. They have to be under one of the Tatura GPs to go into that hospital, but she has such skills in palliative care that it works well. Other than that they come in here to the medical ward. It is not ideal.

In-home respite would be fantastic, and I know over the years that I have been in palliative care we have talked about whether or not to get, like South Australia does, the packages. You would have a package for the last week of life and a package for the last months of life, and then you would be able to put someone in overnight. We are looking at that at the moment with GV family care. They have got a group of carers who look after quadriplegics who have quite high skills. They are only personal care attendants, but I am just having meetings with them at the moment and getting costings on what it would cost for one of them to go in. We have surveyed families and we have surveyed carers and patients, and one of the things they say is that if someone comes into the home overnight, what they really want is a registered nurse. The cost of that is ridiculous. I have just done the costings with family care for these personal care attendants, and it is \$700 for one of them to sit overnight with someone.

Mrs PEULICH — But, Carmel, sometimes they just need 3 hours to do the shopping, and you do not need a nurse for that.

Ms SMITH — That is right. No, you do not. Some of them need a good night's sleep — that is what they ask for. Even if we can get those carers, those PCAs, up to a level where they have got experience in palliative care, they can still ring one of us who is on call anyway for that backup.

Our volunteers do the shopping. If the patient wants to go and get their hair cut, they are in with the patients for that sort of thing — for the carer to go shopping or for the carer to have a massage, some time out, a cup of coffee with friends and things like that. Our volunteers will sit with them during that time.

Ms SPRINGLE — I am not quite sure whether this is going to be a question you can answer, but given that you obviously have quite a reputation for the good work that you do, what do you think has made the difference here in Shepparton in terms of how the organisation has been set up, how it operates, how it has grown and its success? What do you think has been pivotal in that that perhaps has not been emulated in other regions?

Dr HETHERINGTON — Community input. We have talked to people in neighbouring areas and neighbouring regions, and we have frequently heard the comment, 'If it's a matter of health care and if it's needed, the government should provide it'. That is quite a common opinion. We do not subscribe to that. As a community we said, 'We want something, and we will go and get it, because we will raise money'. We are paid by government grant per capita the same amount as everybody else in the state, but we require another 40 per cent on top of that in order to provide the 24/7, because government funding in Shepparton would provide for Carmel supervising district nurses, community nurses et cetera. There is a huge difference between that situation and 24/7 by nurses who are specially trained and who are a small group so that all the patients tend to know all the nurses and all the nurses tend to know all the patients. So size is a critical factor. It has been suggested that our model of care is good, so we should expand. The answer is: no; we should seed the next one and the next one. We have offered to do this. We have offered to go and tell people how we got started — no response.

Ms SPRINGLE — Just to clarify, when you say it is about the community, has that happened organically or have there been pivotal people who have kind of organised a grassroots buy-in?

Dr HETHERINGTON — Yes. Twenty-seven years ago there was a very energetic, spontaneous committee. I do not think they even called themselves a committee, but by gee they were persistent and they spread the word and they collected the dollars. When we started, of course nobody in the community knew what palliative care was, nobody knew what a hospice was. As time has gone by we have touched nearly every family or a lot of families in the region, so they now understand. The understanding is there and with that is the will to contribute. If we go and rattle a tin, it is not 'I'm too busy', it is 'How much do you want?', and that is what we have created in this community.

Ms SMITH — I think, too, just after I started with hospice, there was a process going on around tendering, and I was in oncology over at Shepparton Private and, because a lot of my patients used this service, I supported our application. The committee of management then fought very hard to maintain our model of care, and from what I have heard from the community over the years, places like Geelong and Bendigo that had the same model that we had lost it in that process and they have never been able to get it back. The committee then fought very hard for us to be funded in our own right and maintain our 24-hour model of care, and they were successful in doing that. It is just gone from strength to strength from then.

Dr HETHERINGTON — It was a battle, though. I mean, we were trying to maintain a model of care which just did not fit, and coming onto this one, as soon as you mention 24-hour care to an accountant, the bells ring — because the bottom line is going to be horrible. We have found that that is not the case, because what happens is that our families and our nurses are so well known to each other that tonight's possible disasters are foreseen and catered for, so there is not the 2 a.m. call or if there is it is a phone message. Therefore, the patient does not go into hospital and therefore the \$890 a day or whatever it is for a patient to be in an acute hospital is avoided. So the accountancy of all this works in favour of good community care.

Ms SYMES — Thank you so much for your testimony today. Just picking up on the point that you raised in relation to the restrictions on drug administration, I am keen to hear how you would like to see it work.

Ms SMITH — As in, restrictions on — —

Ms SYMES — On the fact that family can give drugs and — —

Ms SMITH — Oh, yes. We are just starting to get into the disability areas. We have not had a lot of patients die in supported homes, but that is something that we feel is very important. If we have someone in a home who has been living there for five or six years, it is their home, so they should be able to stay there.

On the issues around access to medications, they have nowhere to lock them at night, and they have to lock them because of the safety of the other residents. It is much easier in a family's home to do that than in a supported government house, and a lot of the workers who are there overnight cannot administer s8s, which are the opioids or those medications that we are using. I do not know how we get around that, because it is a costing, I guess, if they had medication-endorsed div. 2s do the overnight call on that. That is something we are still working on.

We have one or two successful deaths in supported houses, and at the moment we have another lady we are involved with, but it is difficult, because their opt is to ring us and for us to go out, and is that our position when that is their home? That are the difficult ones that we do. Other than that, from a medication point of view, one of the issues that we had a few years ago was around people whose needs escalate. If you are preplanning someone's end-of-life care, you might get so much of the medications you think they are going to need in place weeks before it happens, but their needs might escalate in that time.

One of the things that we were finding was that sometimes you would get a call in the night that Mum had deteriorated and you had to go out and start a syringe driver for end-of-life care, but since you set it up their needs have changed dramatically, and they might not have enough drugs, if you had got one box of five ampoules and they needed seven ampoules to set up their syringe driver. So we actually got a poisons permit so we have a stock of medications at our office that the girls are able to access after hours for emergency use. They still need a doctor's order. They have to have a doctor's order to cover it, but it means that they are not having to come in here because you cannot get medications in the middle of the night.

Ms FITZHERBERT — Thank you. I have a few questions, if we have time. The first is that you mentioned earlier the importance of working with GPs, and that is something that has been described to us in other hearings, and you mentioned that there are difficulties if GPs will not prescribe the drugs or sign the death certificate. Could you just elaborate on that a little bit for us?

Ms SMITH — For us in Shepparton, it tends to be the new overseas doctors who are coming to town. Some of them do not have any understanding of palliative care at all, and certainly do not believe people can die at home. Their attitude is that they are too sick to be at home; they need to go into hospital, so is working with them. Usually once a year in the past, but now that the Medicare Locals have finished and the new health networks have started we have to see how that is going to go I meet the new doctors that come into town every year. We usually have it at hospice house, so that they know where we are. We talk about what palliative care is, what we can do. It has been really good but there still are some of them who will say to us, 'I'm not comfortable doing this, and they will need to get another doctor'. That is fine, but we need to establish that early in the piece.

Ms FITZHERBERT — So that is the answer — you just find a different doctor. if it cannot be talked through?

Ms SMITH — Yes. Probably in the same practice, if we can, but sometimes it does mean that. We also have to check all the doctors as they come into town, on AHPRA. Some of them have restricted practice, so they cannot look after someone at the end of life, because they cannot prescribe s8s.

Ms FITZHERBERT — That makes sense.

Ms SMITH — So we need to find that out.

Ms FITZHERBERT — You mentioned also that you use an IT program that hospitals can access.

Ms SMITH — Yes.

Ms FITZHERBERT — What is the program?

Ms SMITH — It is called PalCare. A lot of the big services in Melbourne — Eastern Palliative Care, South East — have got it; Ballarat Hospice has just started; Melbourne City Mission has got it. It is actually an IT program that is specifically for palliative care patients. There is a user group that we have that meets twice a year. It is a fantastic program, but it costs monthly. Everyone says, 'Why don't hospitals have it?'; well, it costs money.

Dr HETHERINGTON — Like a lot of the things. As I mentioned earlier, being able to be proactive enables us to do these things. The amount of money we have had to spend on security for our staff, on telephones that are dead man's telephones, and what do they do when they are in a difficult home situation, are they at risk? All of these things have to be brought into account. We do have situations where we have said: nobody goes alone. It is rather horrible to think how many of these dollars are going to what is called health care, but they are not; they are going to sort out another of society's problems, but it is expensive.

Ms FITZHERBERT — I have one more question that was just on funding, if you do not mind. You mentioned earlier the struggle to maintain the funding when other comparable services have lost out some years ago. This might be a very basic question, but what is the funding that you access to do what you do; is it state or federal, and what is it called?

Dr HETHERINGTON — It is state, but some of it comes from the feds with a string attached. It has always been complicated. It has been simplified to some extent. When palliative care services started, they were not part of the original Medicare agreement. They are now. We get money just from the Victorian department of health.

Ms SMITH — Health and human services.

Dr HETHERINGTON — Yes. We do not get any federal money directly to us.

Ms FITZHERBERT — Sure. What do they call it? Which particular money is it that you get?

Ms SMITH — It is in the subacute funding. We have moved around a bit over the years, but I think we are back in subacute.

Ms FITZHERBERT — It is often the way.

Ms PATTEN — Thank you for the really inspiring work that you are doing. Having listened to Ms Cudmore earlier, it is so impressive that for so many of the problems that people have raised for us over these hearings, you seem to have found solutions, which is very impressive. That is why I wanted to ask you: one of the problems in regional areas, particularly about rural and remote patients, is that it is a 80-kilometre drive. You do Greater Shepparton. Do you have any ideas on how some of those much more remote patients could be better served?

Dr HETHERINGTON — Accommodation would be the thing, would it not?

Ms SMITH — We have patients who are out the back of Murchison and Rushworth, quite isolated patients. I still think it is the planning. If you have pre-empted and planned their care in such a way that they have things in place if a disaster happens — if their pain escalates or if they get a new symptom or if something happens, you have got something in place. It is no use driving out there if there is nothing you can do. So I really believe it is the preplanning with that family around the scenarios. That is what palliative care does very well. If you have got someone with a fungating neck wound, the chances of them having a catastrophic bleed are fairly strong. If they live way out in Woop Woop, you are not going to get there before the patient dies, but you need things in place for that family to manage that, the dark towels. We all do it, but you need to have preplanned it, and I think that is what palliative care does well: we pre-empt things that are going to happen.

Communities rally around those folk, especially the farming communities. Neighbours will keep an eye on things. They have blind up, blind down if there are single men living out there, so that someone driving past checks. Everyone seems to come on board. If that patient wishes to die at home, my experience is that people — family and community — will do everything they can to support that.

Dr HETHERINGTON — There is a lot of training needed, though. We believe that we are good at training our families so that they can help themselves, with our assistance as well. Before that, there is a lack of understanding in the community of palliative care. Somebody referred earlier this morning to a Q&A program and those ribbons that come across the bottom. There was one which said, ‘I would rather die than put up with all that palliative care’. I mean, really! If that is an understanding in the community of what palliative care is and can do, we have got a long way to go. We are all right locally, but nationally, God help us.

Ms SMITH — You were talking before about the advance care planning. That has been in the background at Goulburn Valley Health for a while, and we are doing Respecting Patient Choices. We are part of that committee and looking at that. The problem in the past has been that people, especially in the aged-care facilities in Shep, have been using Respecting Patient Choices for years, but nobody in emergency — —

Ms PATTEN — Knew it.

Ms SMITH — No; that is right. It is about all being on the same page and believing it. My big bugbear that I really struggle with is that people think that we go out and sit with these families and just talk to them all the time every time we see them: ‘Okay. You haven’t died today, but it’s probably going to be soon’. You do not have those discussions every time you see them. You might go there a few times, and it is often then that they will bring it. Then they have to come into casualty and have some young doctor say, ‘You know you’ve got a terminal — —’. ‘Really? I didn’t know that’. I think we need to get processes going where we all know where the patient is at, what discussions have been had and where they are at, so they do not have to go over their story.

I will tell you just one funny story. Years ago we had a young fellow in the medical ward. He was a Dutch boy, and I actually went to school with him in my youth. Anyway, one of the nurses was on call, and he rang her up. He was very unwell, and he had just come back. The last thing he had wanted to do was to go fishing up at Alexandra, which was something he had always done. So we organised it with the Benalla district nurses. He went up there with his oxygen concentrator, all the gear and everything, and he had a wonderful weekend. Anyway, he came back, and he was not well. He went into the hospital, and he rang Sonia at about 10 o’clock on the Saturday morning and said, ‘There’s a real problem. Are you allowed to come up?’. She said, ‘What’s

the matter?'. He said, 'They want to put me in an incubator'. She said, 'What?'. Anyway, she went up and sorted it all out. Some doctor had come in and talked about him being intubated. He said, 'Oh, no. We've talked about that. I don't want that'. He just got all the language wrong. He was quite comfortable with his end-of-life care and his death, but somebody just threw a spanner in the works. You tend to troubleshoot and do a lot of that sort of stuff in palliative care.

Mrs PEULICH — I have two quick questions and one just requesting a little bit more information. The isolated and sole-person households, when they come onto the palliative care program, what additional needs or support services do you have in place for them, and can you give a couple of examples?

Ms SMITH — I guess you have to rely on neighbours. Sometimes it is just not possible. It is about being comfortable with having that discussion with that patient to say, 'Look, I know this is what you want, but the reality is we'll keep you at home for as long as we can, but it mightn't be in your best interests or in the best interests of your neighbours for you to die here'. It is having the courage to have that discussion with them.

Mrs PEULICH — Would they then be part of the 15 per cent who do not die at home, or a substantial component?

Ms SMITH — Yes, but they would come in here.

Mrs PEULICH — When you say that people come onto your books, what criteria do they have for you to accept them coming onto your books?

Ms SMITH — We have a triage process, and sometimes they are appropriate and sometimes they are not. We probably have 20 referrals a month and admit maybe 12 to 15 of them. We have a process that we go through about where they are and what their disease process is: are they still having active treatment, do they accept or consent to palliative care coming in? If they still want full resuscitation and that sort of stuff, we are not really good at that, so we will probably have that discussion with them and say that maybe it is not appropriate. But sometimes we might get involved with that patient, because we know that even though they are not ready for us they will consent to us getting in a little bit, and then as they get to know us they will stay.

Mrs PEULICH — The last question is: you said a percentage come out of the palliative care and go home. What percentage would that be?

Ms SMITH — We would probably discharge two a month. They are not big numbers.

Mrs PEULICH — So that is like 0.0-something?

Ms SMITH — Yes.

Mrs PEULICH — Can I just say that from your evidence it appears that you run an exceptional service, and I want to congratulate you on that.

Ms SMITH — Thank you.

Mr MELHEM — Just one quick question. Do you think the current law is adequate to give people a real choice about end of life? If you think it is, obviously that is the answer, but if you do not think it is, what do you think we should change?

Ms SMITH — I do not know how to answer that. How would the law change someone's choice of place of death?

Ms SYMES — Or are there any legal barriers to your work, perhaps might be a better way of phrasing it.

Ms SMITH — I do not see any legal barriers if you are working within your scope of practice. I do not see that there is a legal barrier against it. If someone's choice is to die at home, their GP is involved, their decisions are sound and they have people who can help them in that, I do not see that there would be a legal issue with that.

Mr MELHEM — I mean, voluntary euthanasia, for example; is that something that we need to go and have a look at?

Ms SMITH — It is out there all the time. I have to say that in my 12 years with the service we have had two that I know of that have sourced what they needed for their end-of-life care overseas. We probably were suspicious of it, but it was never discussed with us and they never involved us in that decision. When it happened there was a note on the door to say that we had no active involvement in it, because we cannot. It is against the law and it is illegal.

One of the interesting things I was thinking about, when you were talking before about the sedation with your dad, is it is an interesting thing that we do with the Aboriginal community. It is really important for them at the end of life to see their loved one talk to the spirits, because they believe then they will go over to the Dreamtime better, so using sedative drugs is something that we probably would not do a lot with them.

Mrs PEULICH — And my brother, with whom my father had been disconnected, was able to come and see him while he was still alive.

Ms SMITH — Yes, so families will often ask us to back off. That is against the law at the moment. When it comes we will all have to deal with it. I do not think I would like to give someone a lethal injection, but someone probably will. Maybe I will be wanting it!

Dr HETHERINGTON — It has become apparent to us that a lot of the clamour to legalise euthanasia comes from a misunderstanding of how good life can be made by proper palliative care. Obviously it is not always successful; there have to be exceptions. But nearly every time good palliative care will allow death to occur with dignity and comfort. That is what we are striving for. If the law changes and physician-assisted death becomes legal, we are all going to have to do an awful lot of rethinking of where we are. I speak now as a medical practitioner rather than the administrator, which is my role with Hospice Care. We are taught to look after the patient, the whole patient, so it becomes a philosophical argument as to whether you include the right to die in the care of the whole patient. I think a lot of medical practitioners and nurses are going to find it very difficult to include that notion in their standard practice. It is a very difficult area. Surprisingly, though, for palliative care — surprising to most of the population — we can create a situation where patients do not make that decision and that is what we are proud of.

The CHAIR — On that note, Ms Smith and Dr Hetherington, thank you very much for your presentation today. I would like to thank Ms Smith particularly for your assistance to the secretariat in directing us with who to speak to and where to go today. Thank you both very much, and congratulations for everything you do in the community. It really is a remarkable model, and other communities should take up the offer that you have got on the table. Thank you very much for being with us today.

Dr HETHERINGTON — Thank you for the opportunity to express our opinions.

The CHAIR — Just before we close for a brief recess, I would like to acknowledge Mr Dale Fraser, who is the CEO of Goulburn Valley Health and is in the audience today. Thank you for your hospitality today, Mr Fraser. We really appreciate being here and being able to speak to so many of your senior staff

Witnesses withdrew.