

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Warrnambool — 30 July 2015

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Dr Emma Greenwood, Medical Director, Palliative Care, and

Ms Sue Marsh, Paediatric Unit Manager, South West Healthcare.

The CHAIR — I declare open the Legislative Council’s legal and social issues committee public hearing into the inquiry into end-of-life choices. It is terrific to be here down in Warrnambool at the Lady Bay. I would like to welcome Ms Andrea Janes, a project worker for the Improving Care for Older Persons initiative and a registered nurse; Mr John Quinlivan, nurse unit manager, medical/palliative care inpatient unit with South West Healthcare; Dr Emma Greenwood, medical director, palliative care, South West Healthcare; and Ms Sue Marsh, the paediatric unit manager at South West Healthcare. Thank you very much for being here today.

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 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 an hour and a half for your presentation and for questions this morning. I invite you now to make your presentation, and then afterwards the committee will have questions. Thank you again for joining us this morning.

Ms JANES — On behalf of South West Healthcare, the four of us are very proud and privileged to be involved in this process. Yesterday I believe you met with Julie from the south-western consortium. We are affiliated with them, and you are also meeting Portland and Hamilton later today, which we also assist with in the subregion consultancy team. But we are going to mainly focus our topics this morning on actual South West Healthcare delivery of palliative care services and end-of-life care services. The community team consults with Portland and Hamilton and provides the service there, so we are a consultancy service, but we have chosen not to speak about that today so that you can ask more direct questions to Portland and Hamilton.

The CHAIR — Thank you.

Visual presentation.

Ms JANES — As there is an abundance of information which I am sure you were given yesterday and will be today and throughout the whole of inquiry, we have the folders there which have South West Healthcare-specific information. I have put together the palliative care draft of our framework, which is all our policies in first-draft versions — currently with staff members at the moment. You have also got brochures on what our staff within the teams do. I have a map there of our service area, and I also highlight the area that we can only provide 24-hour nursing care support to. There is the end-of-life care pathway, which we use in the inpatient unit — there is a copy in that.

There is a copy of the carer needs assessment tool, which is how we identify what carers actually need and their requirements during different times through their care. On your pen, the end is a USB stick and the whole advance care planning strategy is on that pen. There is nothing specific about what we do there, but the advance care planning officer thought you might like that.

The CHAIR — That is very impressive!

Ms JANES — I did not get one, I would just like to say! Michelle thought that would be useful. That has got the whole strategy and policy for you, rather than hard copies. That is where we are at.

South West Healthcare is committed to providing a comprehensive range of healthcare services to enhance the quality of life of people in south-west Victoria. South West Healthcare provides extensive medical, nursing, mental health, allied health and community health services. Our vision at South West Healthcare is to be a leader in providing innovative and quality health services, and our mission is that we are committed to providing a comprehensive range of healthcare services to enhance the quality of life for people of South West Healthcare.

An integral part of the service delivery at South West Healthcare is the palliative care component. Palliative care at South West Healthcare is provided for people of all ages who have a life-limiting illness with little or no prospect of cure. It is provided throughout the community program, the palliative care inpatient unit and the paediatric unit. As a nurse, I strongly believe it is a real privilege and a honour to be involved in someone’s

end-of-life care. I view it as being very similar to you are welcomed into the world and it is a very important event in your life, and so is going out if we can assist with that, so it really is quite an honour to be involved in palliative care nursing throughout the region.

I have given you a copy of the map. The red lines are where we cover as a community team. We cover in excess of 400 kilometres in a roundabout circumference, but the only area that we can provide 24-hour nursing care support and backup is the little highlighted shade, which is the town of Warrnambool. There is quite a big gap after hours — you get phone support, but we cannot provide that nursing care backup. That is one of the inequities of the service at the moment.

Part of the community team is we have a nurse consultant coordinator, which I am currently in the acting role of. We have three nurse consultants who are 0.8 EFT each. We have a medical director, a medical intern, a palliative care counsellor, a palliative aged-care support nurse, a coordinator of volunteers, a volunteer pastoral care worker and a cancer link nurse. The advance care planning officer lives in our office but she is not directly linked to palliative care; it is more of an all-hospital approach. I manage her position.

The palliative care community — we cover from Macarthur, Lismore and Camperdown to the coastline, down to the Twelve Apostles, right back around to Port Fairy and everywhere in between. That approximately is over 400 kilometres in circumference and also the inner area. With three nursing staff four days a week, it can be quite challenging at times. We cover that area from the moment someone is put on admission to the program through every stage and phase of their care, right until 12 months post their death for the bereavement of the family. That support is provided. We have delegated areas for our nurses to work within so that we provide a consistent approach to patient care. At any one given time we can have up to 75 patients on the program. We do not have a waiting list; we take everyone. There is currently no waiting list for palliative care at Warrnambool for the community. I know other places do have waiting lists, but we are very adaptive as to how we can squeeze everyone in.

As I mentioned, there is the inequity in the service in what we are able to provide to our rural and remote areas in terms of 24-hour backup and care. The medical director, who is Dr Emma Greenwood, provides assistance for specialist medical care in both the community and the inpatient settings, and also will assist us with doing home visits and GP education. We have been very lucky this year to be assisted by a medical intern — a palliative care intern — so that has provided the ward and the community with more of a backup service. If Emma is out with us, the ward has got someone to call on or vice versa. That has been invaluable to the service as well. That also helps with our advance care planning component as well for our patients; Emma goes out with the nursing staff to help complete the medical and during powers of attorney and the advance care planning paperwork. Emma is involved with the education of advance care planning with the staff — that is our first health care.

The counsellor also helps Portland and Hamilton; she is split between us and Portland and Hamilton. Our aged-care support nurse assists residential care facilities and disability services throughout the region. She does not actually have direct patient care; she supports the staff in those areas to care for those patients. Her main role is around education, Link Nurse meetings and being there for a support role, giving them the tools to embed the care in their place of choice or their home. We have a coordinator of volunteers, and we have approximately 40 volunteers in palliative care at the moment. I think there are approximately 200 at the campus in total, but we have 40 specifically for palliative care. They do one-on-one visits at home. They will do compilation of life stories. They will also visit the ward. They do massage. They will take people out if they need to get out — take people for a drive. A lot of reminiscence therapy, and that is very invaluable.

We are very lucky to have a pastoral care worker, who is a volunteer. Marjorie Crothers is our volunteer pastoral care worker, and she is able to support us at South West Healthcare and also at St John of God — she visits there as well — so patients who are in either hospital are able to receive her visits.

Just some stats in terms of community service delivery, last year, for the business year, we had 146 referrals. Total contacts were 3849 — 45 per cent of these were face to face, 53 per cent were over the phone. Telephone contacts include phone calls to GPs, other service care providers and the district nursing service to coordinate the care of the patient. It also includes phone calls to patients and carers. Sometimes the carers will ring, themselves, for advice and want to organise meetings to catch up about their loved ones. Also those contacts would include the 12 months of the bereavement phase as well, in which we support the carers and families.

We had 24 discharges from the program — not deaths; we actually had 24 people leave the program — 58 per cent of those went on to other healthcare providers, 17 per cent were discharged to other specialty care providers in palliative care, we had a couple move regions, we had a couple who were able to stabilise and did not need our specialised service anymore so they were then referred on to GPs or went into nursing homes. To make our service more, I suppose, intensive in the community, once people get into residential care, we are then referring them on to the aged-care support nurse so they are supported in their residential care and we can focus on people in the community and inpatients as a service. With the support of staff, they are still getting their support, and because they are in a facility as well. It is a bit difficult; you have to work out how you find that fine line as to where you put your resources and time. Because they have already got supported care, it makes more sense for us to spend the time with people who do not have the care and the support.

We had 122 deaths last year. Forty-one per cent of these were in the palliative care inpatient setting, and that was either with John or in another palliative care inpatient setting; 30 per cent were in residential aged care; 20 per cent were at home in private residences; and 11 were in an inpatient setting which was not palliative care, so they might have been on a different ward or in a different — Terang hospital or Timboon hospital, so other places.

John is going to give us a bit of a run-through on what the inpatient unit does.

Mr QUINLIVAN — I am John Quinlivan. The palliative care unit is within a medical unit, so there is a 26-bed ward and within that there are 6 beds which are designated for palliative care. I have a team of nurses — five trained palliative care nurses — working in that area. Within that, we also have multiteam with allied health staff such as OTs, physios. We also have speech therapists and things like that. We also have Dr Emma Greenwood, who is there on Mondays, Tuesdays, Thursdays and Fridays. We have just been allocated a resident doctor to support that, which has been really good. Within that, with allocation for treatment, the physicians are involved with the treatment of patients within the unit, and Emma Greenwood overlooks that as well. We have a social worker who is involved also with community health, but we also can get other social workers in who are attached to the hospital to help with grieving and things like that.

Overall, with stats, up to May this year we have had 142 separations. Our year-to-date bed days were 1281. Our average length of stay is nine days. We have phases of care, so patients are graded as stable, unstable, deteriorating or terminal. With that, we had 230 different phases. As said, we had 42 per cent of people die on the ward, on the program.

We do have an end-of-life care pathway which we use. That has come from the Liverpool care pathway model. That was introduced. We were one of the first units to trial that through Eric Fairbank a long time ago now; about 2002 or 3. We have gone through a number of changes. We are using stage 11 of that; I think they are up to stage 13 or 14. We are looking at reviewing that, and we have been taking stats — time of compliance with documentation and things and that is lacking, so it probably needs to be reviewed. There is statewide looking at the care pathway itself.

Within that, sometimes the ward can have 2 or 3 patients in for those six beds, but at other times we can be up to 12, so therefore they move into the acute sector as well. Sometimes we might have some acute patients in the actual unit, and then other times there will be palliative care patients throughout the ward, which puts bed pressure on and things like that as well. That is basically it.

Ms JANES — Sue is going to talk to us about what involvement we have with paediatrics.

Ms MARSH — As you would know, there are limited paediatric palliative patients around, which is a very good thing. In Warrnambool our catchment area is every patient who comes to see our paediatricians really, so we can go over to Heywood — we have had patients over that way — up to Casterton, to Lake Bolac and around, so our paediatricians draw from a large area. We look after children with — in palliative care congenital and usually oncology disorders are our main thing.

Our service delivery model is one that we do individualise for every patient. It very infrequently occurs — we have had one this year; we had two last year — it probably averages between zero to three patients a year, where we provide palliative care. Over the last five years we have done home-based palliative care because the majority have been within the Warrnambool area. Our palliative care is arranged through our nursing staff on the ward. We would have a child who may come in who needs some care, and we have four or five dedicated

nurses who are happy to provide out-of-house care — to visit their home — which is done during their work time on the ward, and sometimes they may work and then go into the home afterwards, and we reimburse with time off in lieu. We do not have any specific funding for it.

It is a project or something that we like to do because a lot of these children we have looked after for a long period of time, and it is something that we feel we need to do to help their families through their end-of-life care. Our last one, we spent three months, twice a day visiting a family at home in Warrnambool — from the ward, with only four staff rotating through — so it is quite time consuming, but it is very rewarding, very valuable and the families get a lot out of us providing care.

All our referrals usually come from Melbourne — from tertiary institutes. Sometimes they are timely referrals and sometimes I feel we are reasonably late in meeting the families. We have children who are born with congenital disease, who have been known to be dying from birth. They are non-curative, but we might meet them a week before they come back to Warrnambool, and that often places additional strains on our resources.

Specialists involved — we work with the Victorian paediatric palliative care, with the oncology. Some of the congenital disease, we do not have a lot of input from them when they come down here, and some of them may not even know that they are in our local area. The paediatricians we use are excellent. They do home visits, and at the terminal phase of their end of life they will actually stay in the house with us while we provide care, which has been great for us, and unheard of everywhere else I am sure.

We work with Very Special Kids, who often have links with these people. They are a really good resource for us. We tap into palliative care for services with the social work department allied health services. Funding for palliative care equipment comes from the VPPC in Melbourne, and we try to individualise care to the needs of that family and that child. We are a bit limited as to where we can travel because we work from the ward area and that, so the majority have been in the Warrnambool area. We have had the ability to go to Cobden, which is out the road, sorry, for a child that we actually did not know who came in and was going to die within a few days. We were able to do some outreach services to them. I have provided services in Heywood I have done that previously, but in general it is in the Warrnambool catchment area. That is our paediatrics.

Ms JANES — Our governance structure for our palliative care program. We have the department of health for strengthening palliative care strategies, so points 1 to 7 we comply with. We also have the department of health advance care planning strategy. Our formal accreditation is through the EQUIP National standards, so 1 to 10 was last year. We are linked in with the Barwon South Western Region Palliative Care Consortium. Internally at South West Healthcare we have a newly formed cancer and palliative care governance committee, so that will look at cancer care from diagnosis right through to death and the service that we provide. That has a multiteam approach.

We also have an advance care planning committee, and we have a palliative care working party. We have got consumers on all those committees. Our main consumer one is the palliative care working party. We have done a bit of a revamp this year and recently we have actually followed through with a patient story. We had the wife of someone who had died on the program and utilised both St John of God and South West Healthcare. The ambulance was from Nullawarre, so 25 kilometres out the road — there was no service in town — so we have done a patient story on that.

We have identified eight issues that we can change. We are working on those at the minute. The first one we tackled was equipment, because we thought that would have the best impact for everyone on the program if we made those changes. We have had consumers involved in that, and where we are at at the moment is that we have identified that it is great that hospital staff know how to use the equipment, but when you are in the home and you do not know how to use it, what do you do? You might have someone over the phone — the shop is actually compiling cheat sheets or information sheets on step-through. The three consumers on the committee are going to go up to where the equipment is located and try those sheets out and say, 'Yes, this works. No, this doesn't; I can't understand it'. We are trying to be more consumer focused in the information that we give patients, and we are trying to support them better that way.

It also brought through issues with the ambulance service terms of coming to South West Healthcare as opposed to a direct admit at St John of God hospital for a palliative terminal patient. It brought through some other issues of carer distress and fatigue. We also had medications in the home. That is an issue that the lady brought up; out on a rural farm she actually felt quite scared with the amount of medications that she had in the house. She felt

quite vulnerable with the possibility that if someone did come to the house and demand those medications, what would she do? She spoke very long time about that, around the medication vulnerability, especially out in the community. We are just working through steps around that at the moment.

It has been a positive change so far. We have only had four meetings this year, but we are going to go back to quarterly meetings now that we have got it up and running and more sustainable so they have got a bit of momentum. That has been really valuable. Previously consumers were coming along but they were not having an input, so we have changed the whole structure of the meeting so that they feel like they can speak and we can actually get what they want to contribute. That has been really good so far.

Respite services, so access for us for respite services — there are very limited respite services available, and most of it is depending on where the patient lives. In Warrnambool City Council there are aged-care facilities which provide limited respite services in an inpatient setting. In terms of in-home respite, it is very difficult to facilitate in Warrnambool and in the wider region and community. We use commonwealth care centre carers who run through Barwon, Lyn Boyd. She has fed back to us that the biggest difficulty for her to provide in-home respite is the cost. It is much more economical for respite to be undertaken in a nursing home facility rather than in home when you are looking at 24-hour respite.

We are also finding now that because our patients are younger, over 65 is okay for residential care — they can go through the whole ACAS trail — but if you are under 65, it becomes very difficult in how you link because of access to ACAS and all of those things. Age is one barrier. We do a lot with the Moyne shire, the Warrnambool shire and the Corangamite shire. When we are ringing and asking for home and community care assistance or funding, one of the major issues they are having — a theme probably in the last three months is that their funding has been cut, their hours have been cut, so they are not able to help us like they were. That is becoming a problem for carers at home, so then it is more stress on carers. Families are having to try and outsource in other ways, and often there is not another way for us to provide that respite for the carer. Our volunteers do not do hands on. They will do one-to-one visits, but they will not actually do care provision, so that is very specific in that. That is becoming a bit more of an issue. It is probably more of an issue in the rural setting rather than in Warrnambool and regional.

We are also finding that this year there is an increased occurrence of financial support or financial assistance. Every year we get a bucket of money from the Cancer Council Victoria, and we are able to give that money out — there are criteria — to people who we identify to be in financial hardship. Last year we had money left over, so that went topped into. This year all the money is gone. It was finished by June, and that is because of the increased demand. I spoke to the cancer council about that. Last year what happened was that people were given \$200 each, and what we do is give it in terms of vouchers for fuel or food — so Woolies, Coles or IGA. It is never cash, so it takes the pressure off that way. Another one we did was we paid for a man's medications through our pharmacy because they could not afford to do it — they had bills around town and it was becoming quite a problem. I spoke to the cancer council about this, and we are not alone. We thought, 'Are we being too generous? Do we need to give everyone \$100 and spread it out further?', but there is a consistency across the state this year that everyone is asking for a bit of a top-up in funds, so they are looking at a top-up. It is good to know that we are not alone in that area, but it is becoming more and more of a problem.

We have just got onto another fund called Stand By You, which we are going to tap into for our patients. Patients can actually apply directly — we do not have to facilitate that — so we are going to give our patients that information, and that is for anyone with a cancer diagnosis. But then it is very difficult for your non-malignant diseases — your COPDs, CCFs and renal — as there is nothing out there in terms of funding, because these are cancer specific, so we cannot tap into it for our non-malignant diseases.

Mr QUINLIVAN — Which is increasing.

Ms JANES — Yes. Non-malignant is becoming a bit of an issue with the funding as well. Respite is very limited, and in our palliative care beds there are no designated respite beds as such. It is all inpatient, so at the moment we cannot actually tweak to say, 'Can someone come in for respite?'. We are not sure — that is a bit of a grey area. We will look into that to see how we can manage better with that. Respite is a bit of a problem down here.

After-hours support for patients in our program, everyone gets 24-hour phone support. Did Julie speak about Caritas Christi yesterday from the consortium?

Ms PATTEN — I do not recall.

Ms JANES — Okay. The whole consortium of Barwon has employed Caritas Christi through St Vincent's at Melbourne, so when all of our agencies are finished for the day Caritas Christi picks up our whole load. That is done through our PERM — —

Did she speak about our PERM database? We have got a palliative care electronic database.

The CHAIR — Yes, she mentioned it.

Ms JANES — We can tap into that. We can see whoever is on in the region, so Caritas Christi gets a copy of that as well. Our phones get automatically transferred through, so if you are a patient, you would ring the 44 171 number like you do any time of the day and it gets forwarded through to Caritas. They have a list of who we can support in terms of nursing care, so whoever is in that Warrnambool area gets the nursing care, otherwise they try and troubleshoot over the phone. If not, they will say, 'You will need to come in' or, 'Get an ambulance and get sorted'.

In the packs I have given you there is information on our April and May statistics for Caritas Christi. It defines who is ringing Caritas Christi, what they were ringing for, what support they then provided — did they send a nurse out? Did they send them to emergency? I have put that in the pack there for you as well.

One of the biggest limits with our after-hours support is our ability to provide that nursing care after hours. It is great if you are in the town of Warrnambool/Allansford. Beyond that, Koroit does not get it. Beyond basically 5 kilometres out of Warrnambool, it is phone support only. That is a big issue, especially for patients who are maybe down at the Twelve Apostles and very isolated, so that is one of the troubles.

Our district nursing service backs us up after hours, so if we cannot go out, there is someone on call at the hospital every night. The coordinator will despatch them out to the home, I suppose, and they will try and support the people at home so that they do not have to come into hospital. That is through all phases of care. From the day they are admitted they go on 24-hour support, to the day of death. It is more common that they get called out in the terminal phase for medication support and symptom management support, but our patients do ring after hours right from day one of admission, but in terms of nursing it is more in that terminal phase or when they are unstable. That is the support that we are able to provide after hours.

Emma is involved with advance care planning. Do you want to talk about that?

Dr GREENWOOD — In this region, in south-west Victoria, we were one of the earliest sites to pick up advance care planning because of my predecessor, Dr Eric Fairbank, who you will hear speak later today, and his working partner, Mabel Mitchell, a nurse. They very soon after the Austin established their Respecting Patient Choices. Eric and Mabel brought it here to Warrnambool and have been developing it since. Usually in recent years it has had a nurse in the role of being an advance care planning nurse.

We now have Michelle Finnigan in the role at a 0.5 capacity, and she is doing a marvellous job. She is working with the current Have the Conversation program; that is what you have on your memory sticks. She is working through those government-based guidelines to keep us up to speed with what is happening statewide. She and I are going to commence delivering education together to nurses not just from South West Healthcare but also from Portland and Hamilton. They will be coming to education sessions, so they will do the Respecting Patient Choices through the Austin online course, and then they come to us for a day of consolidating. Michelle, our advance care planning nurse, has revised all of our paperwork and our forms that we use in advance care planning, and she has done a wonderful job of getting those all down and uniform so that it makes it easier for people on the ground to do it.

Outside of South West Healthcare, the group Decision Assist is also looking at improving in a primary care setting, especially general practice clinics, knowledge of advance care planning because of the Have the Conversation rollouts and things. On Saturday I am attending a train-the-trainer day in Melbourne where I will be trained by Decision Assist. Clare Chiminello from the Austin will be providing education to a select number of doctors to then go back out to their regions and provide education on advance care planning to the broader general practice community.

We have just set up the governance committee for advance care planning this year, and we are already moving ahead with that. We have some core members who are invited to each meeting, plus some additional people who are invited to some meetings. At our meeting earlier this week we had a representative from the local ambulance service to discuss how these changes were impacting on their service.

The other thing that Michelle Finnigan, the advance care planning officer, has been working on — I have got some copies here to add to what you have got. She has modelled this on a St Vincent's document, or she has looked at all the different hospitals in the state and what they do. Unlike advance care planning, which is held in the green sleeve at the front of a patient's file and carries on from one admission to the next, this form is admission to hospital specific, so every time someone is admitted to hospital they will get a copy of this that will sit in front of their advance care plan. It is more about their emergency treatment. It has not yet been implemented. We are rolling it out next week for one week's trial, and then Michelle will be collecting feedback, specifically from the junior doctors and senior nurses, who will be some of the main people involved in the rollout of this. She will then compile that feedback and modify the form, and she is hoping that well before Christmas we have got the finalised form. The green sleeve with the advance care plan will carry from admission to admission. This will be completed every single time to bring clarity to end-of-life care wishes for that patient for that admission.

As Andrea has written in her thing, we are currently on target with the time lines and requirements for the Have the Conversation strategy.

Ms JANES — In terms of end-of-life care and the pathway John has mentioned — and you have got a copy of what we do as an inpatient — so that is used throughout, on any ward at the hospital, so primarily people will have end-of-life care on medical or the palliative care unit, but if they were on the acute ward, this policy document is used all throughout the hospital. We are not using it in the community. There is a community-based one. We do not currently use it, but we will be looking at using it, and also in consultation with district nursing, because they provide that backup. We will be looking at that, and we will do that at the same time as John does his review. We will have one big overview of South West Healthcare and pathways for end of life, so we will be looking at that.

There are currently 13 aged-care facilities within the region that utilise the pathways. They have a different pathway to us. Their pathways are based on the Queensland model, which was rolled out with a toolkit to all the service providers, whereas ours is based on the Liverpool. Ideally maybe it would be beneficial if there was only one.

Currently I would hate to think how many end-of-life care pathways there would be out and about, but we have seen Ballarat's — theirs is tinkered a little bit as well. I think they are all mainly based on Liverpool. The aged-care one is not based on Liverpool, but for consistency of care and when you have got staff working in different areas, you have got GPs that initiate them, how do you know what each agency is doing? I can see that as being a problem for health professionals. I am sure that the care that the patients get, that is not going to come through in that, but in terms of providing the care, that potentially is an issue, yes.

Ms PATTEN — And knowing what care to provide.

Ms JANES — Yes. I know Hamilton use the Liverpool, and they have adapted theirs as well. I am not sure what Portland uses. Regionally we are going to try and look at doing similar so that we are not all doing different things.

In terms of choice of place of death, all our patients on the program are asked where they would like to have their place of treatment or place of care, and then where they would like to die. Currently we have got 63 patients on the program, so I had a look at the files: 53 per cent of our current patients would choose to die in an inpatient setting; 18 per cent would choose to die at home; and 29 were unsure at the point where they would like to die. Out of the patients who would prefer to die at home, 63 per cent of those we would be able to provide with 24-hour care, but the other 37 who would die at home would be doing so with only phone support as a backup and our business hours support. Then it would be reliant upon carers and families.

The CHAIR — Sorry to interrupt.

Ms PATTEN — Could you repeat those?

The CHAIR — Yes, could you repeat those?

Ms JANES — I was actually going to put them in a graph for you and send them through later.

The CHAIR — Just to clarify what you said before, those who can die at home with 24-hour support would be presently out of the Warrnambool district?

Ms JANES — Yes, so anyone outside of our district nursing catchment, which is basically Warrnambool and Allansford, would not get nursing service at home. I will talk about a patient's story later, about someone who died in Timboon last week on our program. So 37 per cent of those people who want to die at home are not in our 24-hour care. They have the phone support and then they are reliant on family and carers.

Then you look at increased carer strain, stress and the likelihood of whether patients can achieve their goal of dying at home when they are rural. We have one man at the moment who is actually the carer for his wife, so when he dies — she does not have a licence, she is out the other side of Timboon, what happens there? There are lots of little left-field issues as well. I spoke to her about whether she would like some education and support. We are looking at support mechanisms for carers and sessions. She said, 'That would be great; I can't get there'. She does not drive; she does not have a licence. They are on a farm and he is her carer and he is the patient.

We have another couple at the moment; they are in Warrnambool. The wife is vision impaired. He is her carer and he is actually on the inpatient unit and we are not sure whether he will actually ever get home. He came in through chemo as an acute admission last week, acute deterioration. He would like to go home, but whether that is achieved or not, because she cannot care for him and he is not going to die straightaway — he will die, but in weeks — so what is going to happen to that family? We are seeing a few more little left-field things as well in terms of where people want to die and also carers and carers support. That is in terms of rural and remote.

Carers support. We are doing a lot around the carers support needs assessment tool, so our carers are actually being asked to fill out that tool on admission and then in each phase change. That is for them to identify what their stressors are at the moment, so then we can try to alleviate those and assist with their care. The way I have pitched it to the carers is, 'This is for you so that we can see how we can support you better on the program'. They have been quite receptive to that. As you know, a core aspect of palliative care provision is support for family care givers. Patients receiving palliative care have the bulk of support provided by family care givers, and without their assistance — I think we have only got two on the program that do not have carers, which is fantastic, because without carers they cannot stay home and the care becomes quite difficult. There was an anonymous reflection of a caregiver, and I will quote. She said:

I just had no idea what I was in for. If I had known, maybe I would not have been so forthcoming after making the promise to look after him at home. It all sounds so nice when we first talked about it, but it is not at all what I expected.

I am sure that would be a common feeling among carers. It is quite overwhelming at times. We try to empower our carers through education and support in their role as a carer, because they have often gone from a wife or a husband to now a carer in a totally different role and capacity, so this support tool will greatly assist us in what we can do to help carers better within the regions.

Portland do it, Hamilton do it and we do it. I think the whole consortium is going to take the actual tool on board because it is a validated, tried and tested tool. That will be great. When I went through the results for that, there were some main themes that came through. The carers are saying that the main issues they are having is they would like to have time for themselves in the day, dealing with carer feelings and worries, knowing what to expect in the future for caring for your relative and getting a break from caring overnight. They were the top five themes that came through, and that was based on Hamilton, Portland and Warrnambool data in June. We are about to trial it in the community and it has already been done in the inpatient setting.

In terms of around the region, I took the opportunity to speak to our Camperdown campus, because they are part of South West Healthcare, in terms of what they find in palliative care. When I spoke to Rod, the manager there, he said they have had a major increase in the need for palliative care within their inpatient setting. Apparently they are not funded for any palliative care, but in the year 2013–14 they had 22 patient deaths for palliative care, and in 2014–15 there were 41 palliative patient deaths, so they are seeing quite an increase, and they are commenting on the increase in people coming through. I am not sure whether that is related to that people do not want to die at home or feel they cannot die at home or whether they are choosing to die at the hospital. I said

to Rod it would be interesting for us to get some stats around whether this was the patient's choice to die in hospital, or what were the reasons why, because we can get access to those. We are going to try to look at that and see the reason why the increase has occurred so that we can try and focus on it.

Our Lismore campus just provides primary and community health services. They have identified that carer support and education is a priority for their area. They need to educate their carers so that they are confident on their own, especially because they do not have the after-hours support, so they are trying to teach their carers and educate them the best they can to provide the care. Some of their patients are an hour from Lismore, which then would make them 2 hours from Warrnambool. They are very proactive in that they will try to bring them into the community health centre when they are seeing the GP and try to link them in that way as well, because the GPs visit there, or they will go out to the home as well through their district nursing service.

I spoke to the oncologists yesterday — last night we had a meeting — and Terri Hayes mentioned how they are also seeing a difference in what we can provide in the town of Warrnambool as opposed to what we can provide in the rural and regional areas in terms of support and care. Currently coming to Warrnambool are people from as far as Mount Gambier to see the oncologist — —

Mr QUINLIVAN — We are starting to get an increasing number from South Australia.

Ms JANES — And we are thinking that may increase with the new cancer centre next year, with the radiotherapy, so our referral base is going to be wider, especially for haematological disorders — lymphomas. John Hounsell gets a lot of referrals from over the border of South Australia. Ian Collins visits Portland, so a lot of the patients will have treatment there, but haematologically we get a lot come over.

The CHAIR — What is the drive time from Mount Gambier?

Ms JANES — It is 2½. Some are on the other side, like Penola, Millicent, Mount Gambier — —

Mr QUINLIVAN — There is Naracoorte.

Ms JANES — From Naracoorte way they come over here, because I think it is about fifty-fifty: do you go to Adelaide or do you go Warrnambool? So they are right on that cusp. There are limited cancer specialists in Mount Gambier, so the GPs are referring them over here. Whether that will get bigger next year with the introduction of the radiotherapy, that potentially may be an issue.

In terms of consumer feedback, I spoke about our working party before. All our patient compliments and complaints come through. I have only had two complaints in the last six months that I have been here in this role, and they have both been around paying for medications when you are at home. People were caring for their loved ones at home. We pay for non-PBS medications as a palliative care service, but they still have to pay for PBS medications. One family member, who also works throughout the health sector, commented, 'If my dad was in hospital I wouldn't have to pay for anything. We chose to bring him home to die and care for him at home, but then I had to go on and pay for' — this, this and this. Financially that can be a burden as well.

With our unassigned bed fund money, which is what we use for our equipment and medications, we do not have the capacity to pay for everyone's medications on the palliative care program. With 177 people going through the program, there is no way known. I would not get anything else through it, and I probably would not even cover all their medications. That was just one lot of feedback. They were both in terms of payment. Because our service is free, they thought that everything that came with our service would be free, but unfortunately it is not. We have now clarified that in our brochures and things. That was an interesting comment.

To finish on a positive in terms of patient stories — to highlight that things can be done in a rural setting — we had a patient on the rehab ward last week who was termed to be palliative and no more treatment was going to continue. He wanted to go home — they lived the other side of Timboon — so we moved hell and high water to get him home. We knew he was going to die within a week. It was a Wednesday. Ideally he wanted to go home on Thursday. We have delivery of equipment out there, but it was not happening until the Friday afternoon. We fund the equipment delivery, but it costs us three times the amount. We got the equipment out to the house. He went home on the Thursday with an ambulance. He would not have gone home without the ambulance. Then he died very comfortably with his family on the Friday.

With hindsight, we were very lucky we did not wait for the freight and we pushed it forward, but the only way this man died at home was because he had a family member. His daughter-in-law was a nurse, so she was able to provide that 24-hour terminal care out there. He went home with a syringe driver. We could provide all the equipment, but in terms of care provision — the main barrier is if you do not have someone who can care for your 24 hours at home, the likelihood of you being able to achieve your last wish is very minimal in the rural setting.

We were very lucky that the daughter-in-law was able to step in and take over there. The district nursing would go in, like us, every day to do the driver and do the basic care, but you have still got 23 hours of the day that you have to cover. We can only provide an hour, and we would go for an hour, so there is 2 hours. Yes, it is quite taxing and quite challenging, but it can be done.

We have also had a man who wanted to go home at 4 o'clock in the afternoon one day. He did not want to go home — his wife wanted to take him home. We knew he was going to die. We knew we could not wait till the next morning, but we got him home, and he died very peacefully the next morning at 10 o'clock in the morning. He was in Warrnambool, but still logistically to get equipment and things — we did it. So we can achieve things. It is just quite difficult at times. But there are some positives out of it all.

On identified gaps in service, Emma, do you want to talk about anything medically that you have identified?

Dr GREENWOOD — Last year we developed a special letter — we have got a St John of God version for the local private hospital and a South West Healthcare version for the public hospital — to try to facilitate rapid transfer to the palliative care unit for patients who are clients of community palliative care if someone presents to the emergency department and they want to go quickly to St John's, or they want to go quickly to the palliative care unit at South West Healthcare. Because we have such a changeover in especially medical staff in the emergency department, the success of those letters is extremely variable. Sometimes we have had great success with people quickly getting over to St John of God to the comfortable bed or out to the palliative care unit at South West Healthcare to the bed. Other times the patient has still been in for the 7 or 8-hour wait in the emergency department.

We stress on the letters that if there is an acute and new problem that needs addressing, they do need to stay in the emergency department, but we have certainly had people who do not fill that criteria and could just go straight to palliative care who still have not. We are still following up with the emergency department. We are trying to identify why it sometimes happens and why it does not. At this stage we are just having to provide the patients with the letter and warn them that this is our best chance of ensuring this process, but it is not a guarantee. On an ongoing basis we are looking at how we can improve that process.

Mr QUINLIVAN — With TCP — transition care programs — like for rehab, a program like that would be beneficial in palliative care to support people staying home more and support things like the initiative of the Hospice in the Home program. That is something that could be looked at just to help people stay at home if they wish.

Ms MARSH — Probably from my point of view is early referral and advance care planning for children, particularly from a tertiary hospitals that they know they are going to come back into the regional setting. I am not sure what other regional settings do, but our palliative care is only through our children's ward for paediatrics, so if we do not know them and we meet them a week before their death, it is not good planning. That early referral, even just for a 'Hello, how are you' conversation, is very important, and it is missed a lot of the time.

The CHAIR — How could that be fixed? What is the system?

Ms MARSH — I think, too, it is not just a tertiary institution problem. We have started working with our paediatricians, who sometimes will see these children come through, refer backwards and forwards to Melbourne, and not actually think of the bigger picture that they will come back to their home to die at some stage. We are looking at that process. But also through Melbourne — and we have spoken to the oncology services down there — a lot of children spend all their treatment phase in Melbourne, like brain tumour children and we do not see them for any of their treatment. Their radiotherapy or chemotherapy is all in Melbourne. So we are trying to liaise better so that we at least get a teleconference about them early to meet the parents, not

only with medical practitioners but to actually talk to the parents and find out about their families and structures, so we have got something to work on.

With the families we have dealt with, we have spoken to them about it as well, and they would really like just, say, some input. Although it is really difficult to have lots of different services involved when you have got a child, because they have Very Special Kids that currently are run through Barwon. We do have an office here — which is over the recent years — so that should help this service. I think it is a working thing that we are working on slowly, and because we only have one or two a year, it is hard to — there is not one thing that is the issue; every child is an individual, so it is an individual case thing.

Ms JANES — That is it.

The CHAIR — Thank you very much to the four of you for such an informative presentation on the challenges you experience. One of the reasons why we as a committee are keen to come to Warrnambool — and we will be travelling around to other places around Victoria — is just to understand some of the challenges you experience on the ground once you get beyond the metropolitan area. We really appreciate what you have had to say this morning. Dr Greenwood, could I just perhaps ask you to give a bit more detail about the advance care planning work that you oversee and some of the work Michelle is doing that you described. When does that consultation and engagement with patients start?

Dr GREENWOOD — Yes, that is a good question. We did not really talk about actually doing it. We are hoping to train as many people up, both in the hospital environment and in the general practice environment, so that Michelle's role as the advance care planning nurse is really just guiding people. At the moment realistically probably a lot of the advance care planning work that is being done is either by our community team with me signing off on the medical power of attorney, or Michelle has gone in and is doing some work on the ward. With having the conversation, when everyone aged over 18 is going to need to be offered advance care planning, it is obviously not going to be practical for it to come down largely to Michelle and myself. Especially since the advance care planning is going to have to be offered to non-palliative care clients, so it is not going to look at all good to have the palliative care doctor coming and speaking to the 19-year-old — who is expected to recover — about advance care planning. It would be a bit odd.

We see a large part of our role as supporting and training as big a workforce as possible and then providing ongoing support. Michelle and I have a vision that if we can really train up general practices, the nurses in general practices and the GPs themselves, that a lot of this work is going to be done externally to South West Healthcare. We are also working to try to make sure that the paperwork they have access to is consistent with the paperwork we use in the hospital setting so that we are not having to redo things. I guess we are also encouraging people to do things like appointing medical powers of attorney through their general practitioner rather than through their solicitor, because solicitors use a whole lot of different paperwork and charge an arm and a leg for it. As part of our committee we are certainly looking at how we are rolling this out in a bigger community and not just the hospital setting.

Ms PATTEN — Thank you very much. Sometimes it is inspiring to hear what people are doing in regional areas and that you are really outdoing what is being done in metropolitan areas. It is interesting because you think there are going to be greater challenges out here, but in some ways you are doing things better, which is amazing. I was interested in that you mentioned you had 40 volunteers, which is wonderful. Could you tell me about what sort of training they are provided and possibly what other training you think could be of assistance.

Ms JANES — Our palliative care volunteers go through palliative care volunteer training. I think it is an eight-week program, and they cover — —

Ms PATTEN — Is that a certified program?

Ms JANES — Yes, and Palliative Care Victoria came down and did an in-service with them only three weeks ago. That covers lots of different topics from the palliative care process right through to how you approach patients.

Dr GREENWOOD — Confidentiality.

Ms JANES — Confidentiality — especially in a small town — and all of those sorts of things. They go through that, and unless they go through that program with the volunteer coordinator they are not involved in the palliative care program. The other 160 have not done that training, so they are used throughout the mainstream hospital. These 40 are specific for palliative care.

Ms PATTEN — Does this train them in providing medication?

Ms JANES — No, no care provision: no medications, no hygiene — no. It is very much non-nursing and non-medical tasks. They do a lot of hand massage. They do life story compilation. They are quite successful.

Dr GREENWOOD — The groups that do those then receive additional training from the physiotherapist on the massage, and the life stories people receive additional training too on top of just even their basic training.

Mr QUINLIVAN — It is a very good program. A number of them have won state awards for the programs that they have delivered.

Ms PATTEN — Do you see that there would be any opportunity for volunteers to be assisting in respite care, or is that just going too far?

Ms JANES — Probably not within our scope, but as you will hear from the hospice, that is what they have chosen to do with their volunteers; but currently at South West Healthcare it is very much a non-clinically based role, and that is throughout the whole hospital. If you volunteer throughout the hospital, you do not do any clinical tasks.

Mr QUINLIVAN — Palliative care volunteers can feed patients, but outside in the general ward they cannot do that. Does that sum up?

Ms PATTEN — Yes, it does. That is fine, thank you.

Ms SPRINGLE — In terms of the respite care, you talked about there being a real lack of options in that regard. If you do not see volunteers in the long term picking up that sort of role, what is the plan for respite care and increasing that?

Mr QUINLIVAN — We are looking at discussing with our director of nursing shortly in regard to looking at some bed component in the inpatient unit or some respite care, whether that be a week or two, to give carers a rest and that sort of thing. That is where we are looking at at the moment. We have a meeting in August to discuss that.

Ms SPRINGLE — What would be the capacity of that?

Mr QUINLIVAN — That is what we would have to look into, those sort of things. But sometimes the demand on the inpatient unit is huge — we can have 12 patients — and other times it can be quiet. But if we can give carer respite and help them over the hill, then that may reduce admissions.

Ms JANES — What we can do is at the moment our volunteers will go in and spend time with the patients to give the carer a break, so they might go and do the shopping while the volunteer is in — do that sort of thing in terms of respite. The Barwon Carelink, the carer respite that we link into, will provide more funds for the carer potentially to go to see a movie or have time out. There are those opportunities, but, in terms of in-home respite, to have someone stay overnight and care for someone to give you a break, other than the hospice, which has commenced for Warrnambool, there is no — no, no.

Mr QUINLIVAN — There is a huge gap. I think that would be across the state.

Ms JANES — I think that would probably be worse rurally. If you are Macarthur way, Port Campbell or the Otways — that sort of way — there would be an even bigger gap.

Ms SPRINGLE — Currently there is nothing on the horizon for filling that gap, as far as you are aware?

Ms JANES — Not that I am aware of. We have put in for a grant. We find out in October whether we have been successful. nib does grants every year, so we have currently put in for a \$30 000 regional grant for what we have called a carer support package. The money we have put forward would be for a carer newsletter,

bookmarks with all the call information, magnets so that the information is visible, and a carer companion. When I went to the carers conference in Melbourne, through the department, Shepparton had developed a carers companion. It is like a little A5 diary, and it has little tips for carers on being a carer and also places for them to write their questions for next time, appointments, things like that. That has been quite successful. Also part of that grant is to have carer education and support through some sessions in Warrnambool, Hamilton and Portland. We currently have a carer education program and one of the biggest troubles we have is that no-one comes.

Mr QUINLIVAN — We have tried that over a number of years and it goes okay for a while and then it just falls away.

Ms SPRINGLE — Why do you think that is?

Ms JANES — I rang people and went through the tool, and then I said, ‘So if I was to have sessions where you did not have to pay anything; you came along and you had a meal and you met with other carers.’ ‘Yes, that would be great.’ ‘Would you come?’ ‘Maybe not.’ A lot of it was around leaving their loved one. Who would be there? ‘If I went for 3 hours, who is going to look after mum if it is in the evening or if it is in the day?’ I even talked about different times through the day, but there were those barriers. The lady in Timboon — that was when it was brought up — said, ‘I can’t get there. My husband’s the driver’.

Part of the other package is overnight respite at Port Fairy, so for the carer to come and have 24 hours of respite, and palliative care staff would be there. We could do some information sessions, have the volunteers, do fun things, a bit of time out as well, plus being informative, and there was a small take-up on that as well due to ‘What would I do with the patient, with my family member? Who would come in?’. The other thing is there was a lot of guilt around it — ‘I couldn’t leave them’. So it was not only who would care for them, but ‘I feel guilty in having time out for myself’. But one of the major issues that they have raised, through that tool, is that they would like to have more time for themselves. It is that catch 22 and it is very hard.

Ms SPRINGLE — It is hard.

Ms JANES — That is what the carers are up against. They know they need time for themselves, but how do they achieve that? Then there is that guilt. Someone said to me, ‘I don’t need it. There are plenty more people who need it before me’. It is that passing on: ‘I’m not that bad; there is always someone worse off’. It is just part of the carer role, and a lot of these people have not cared for anyone before, let alone their husband or their wife.

Ms SPRINGLE — It is very complex.

Ms JANES — Absolutely.

Mr MULINO — Thanks very much for your very thorough evidence today. It is clear that you are providing incredible services and that you are cutting-edge in a lot of areas. I was going to ask a question about advance care planning and helping people to make choices earlier, but you have already covered off on that, and I think that is obviously a really important area. Another issue that I was interested in is choice of place of death, and it is an area where we have received a range of submissions already. For example, the Grattan Institute basically said 70 per cent of people want to die at home, and they compared that to international figures. I think the department of health had slightly different statistics, although it is providing us with more data on its surveys there.

I was interested in your understanding of it, which is that 18 per cent want to and 29 per cent are a bit unsure. I have a couple of questions. Firstly, do you think there is a bit of a rural-metro divide here, in that maybe people have slightly different expectations because they understand that if they are outside the regional cities they might have slightly more risks?

Secondly, I would be interested in your views of whether or not views of choice of place of death change over the progression of someone’s condition. We have to be very careful with these statistics because it might be that, for example, the Grattan Institute took its numbers from people across the broader community, and of course that is going to change. Fundamentally do you think there is a bit of a gap at the moment in what people are able to experience, and do we need to put more attention into that area?

Ms JANES — I think there is. When I was looking at the statistics last night I noticed — because I was looking at Terang, Camperdown and Timboon and where they have chosen to die — that most of those were inpatient settings, and I wondered whether they felt that they could not do it at home so they wanted to die in a hospital. A lot of the other issues are around the carer still has to go back in that room the next day, they have to live in their house, so if they have had their loved one die in the bed that they normally sleep in every night, there is a lot of angst around that.

We stress on our program that if you make this choice and then you change your mind, that is okay. You have the right to change your mind, and we will try to work with that to get your wish. While you are saying now that you want to care for them at home, if it gets too much, we have a backup plan. We strongly educate our carers that they do not have to do this, because I think a lot of carers feel that the patient wants to die at home so they feel they have to carry through that wish. But at the end of the day it is the carer who has to do that support, so if they cannot do it, we are very mindful of that and we let the carers know that they can change their mind and it is okay. It is not a failure. You have done it to the best that you can for that time and then it is not achievable anymore. We try to draw on the positives of that.

I look at my mum and dad who are on a 400-acre farm an hour out of town, and if they are unwell, the rural community gets around them. I think rural communities potentially have a lot more support from neighbours and communities where they have grown up in, as opposed to if you are in metropolitan areas, you might not know the person four doors down the street and they do not know what you are going through. But in rural communities everyone knows snippets of what is going on and it is a lot more open, so I think that can be a positive as well. But there is definitely a difference between rural and metropolitan support.

Mr MULINO — It does strike me that is a very complicated area, and it might be an area where it is worth us digging a bit deeper and getting a better understanding of things.

Ms JANES — I think so. That would be great.

Dr GREENWOOD — Dr Eric Fairbank, who was my predecessor, will be talking to you later today as part of hospice.

Ms JANES — He is away.

Dr GREENWOOD — Okay, he will not be. His lovely working colleague Deirdre is here, and Deirdre might be able to reproduce that. He has collected a lot of information, and he would be in a very good position to answer your questions. But I think you are exactly spot-on with your idea that it depends on when you ask them where they get these statistics from. Was it just the general community they were surveying? A larger proportion of us are going to say we are going to die at home if we have not had much experience of it. Then, as you say, as the disease progresses ideas change as well. It is a pity Eric is not speaking to you because he knows a lot of information about this.

Mr MULINO — We could follow up with him. The fact that we are much lower than a lot of other countries does suggest to me that there might be a gap there between what we can provide and what people might want, but it is worth drilling into.

Ms JANES — I could potentially, out of those stats, give you what phase of care they are at. We potentially may be able to look at that if you need more information.

Mr MULINO — That would be great.

Ms JANES — What is their answer when that phase of care is. Is it when they are on admission or is when they are terminal? Yes, so we could potentially do some more on that.

Mr MULINO — Thank you.

Ms PATTEN — I just want to follow up on the resuscitation plan and the advance care planning and in particular the dissemination of that information. You have got it inside the green folder and you are asking every day, but if an ambo goes out to the property, does the ambo have that information?

Dr GREENWOOD — Hopefully they would have access to the advance care plan.

Ms PATTEN — Okay.

Dr GREENWOOD — The other thing is we talked earlier about — specifically for palliative care clients — this letter that I have been generating in the last 12 months. We put resuscitation orders on that as well; either I generate that or my intern generates that. We put the original in either the South West Healthcare file, or St John of God, the private hospital, has a way of storing that too. We give a copy of that to the patient, and because it has got their resuscitation orders on it, signed by a doctor, we advise them to show that to the ambulance officer. From our understanding of the current situation with Ambulance Victoria, they are compelled to commence resuscitation even if they know a patient to be palliative unless they have a signed instruction for a doctor saying otherwise. That is where these rapid admission letters have been helpful, actually. I do not know if the Geelong people told you that they re-examined their whole system because they had an unfortunate incident last year with an ambulance and resuscitation of a palliative care client. Did they talk to you about that? They have been speaking to Ambulance Victoria and working with them.

Ms PATTEN — Yes we understand that.

Dr GREENWOOD — We have certainly been involving representatives from Ambulance Victoria with our advance care planning. This document — it is a new document — will be completed for each admission, so it is purely for that episode of inpatient care.

Ms JANES — So the patient will not take it home.

Dr GREENWOOD — That will not be taken home. That will be filed with the progress notes of that admission. The advance care plan — certainly the original — is held by the patient, and again if the patient has indicated certain things, especially things like not-for-resuscitation orders, we encourage their families to present their advance care planning documents to ambulance officers. Having said that, they can indicate that they do not want resuscitation on those. That has been witnessed by a nurse, but will not have the signature of a doctor. That is another thing we have been working on with Ambulance Victoria: can you accept that the person has filled this in and they have done it with their palliative care nurse and they have expressed their wishes, so that resuscitation is not commenced?

Ms MARSH — If I can just add a little bit, with the young child we had, we actually did an advance care plan with the mother and the paediatrician, and we sent it to the ambulance. They accepted it. She was going to school at this stage, so if they got called to the school, they would actually take her home, not to the hospital. They accepted that sort of document, in a local area; it would be different if you were in Melbourne and did not know.

Ms JANES — I think the biggest thing is that we need to encourage people: if you take the time to do the advance care planning and get your enduring medical power of attorney, share it — send it to your GP — because often they are, ‘Oh, the lawyer’s got it’. It is no good in an office when you present to an emergency department.

Ms PATTEN — Which brings me to a supplementary: how are you using technology in this area? I heard Barwon was trying to have all this material electronically stored and attached to a patient file.

Dr GREENWOOD — Yes. We have currently got a facility — our computer program at South West Healthcare is called Trak — and we were trying to add at least a notification that the person had an advance care plan. For a time there one of the reception staff was actually putting the information from the advance care plan digitally on Trak. Another thing that Michelle is setting up, we have an alert system that indicates various things about a patient that shows up with a little emblem next to their name when they are an inpatient, and she is developing a special little leaf that will be displayed. It is to do with Have the Conversation. When the conversation is started it is a certain colour of leaf; when the process is complete it changes to another colour of leaf. You can see whether this person has a leaf and, if so, what stage of the process they are on. We have to educate all staff in the hospital, including the rotating junior medical staff who visit us, to automatically look for that and look for the advance care plan before making decisions with this patient.

Ms JANES — In terms of when people are asked, part of the strategy is that people will be asked when they present to hospitals. We are currently working through with SWARH, which is our IT, overarching. It will start on all admitted patients, so when you come in for admission you will be asked, ‘Do you have a medical

enduring power of attorney. Yes or no?'. If no, would you like more information? If yes, do you have an advance care plan? If yes, do we have a copy? If no, we need a copy. That will not actually go on until we have got a copy in the file.

We are going through the finer details. Because we are a mixture of paper and electronic, we are going through a mixture where we are keeping it with the green sleeve in the front of the history. When we do go electronic, we are trying to alleviate the risk, and we are looking at that at the moment in terms of risk management. If I put Emma's advance care plan on yesterday and she comes in with a new one or an updated version today, where does that sit? How do people know? How do you delete it?

We are trying to look at those behind-the-scenes risk elements. Currently for risk management it is easier to have one copy — the latest copy — in the front of the paper file with the green sleeve until all those behind-the-scenes electronic things are worked out. That is the same with the refusal of treatment. There are questions on admission around, 'Do you have refusal-of-treatment orders and can we please see them?'. That will all go back to the VAE data that data collects in terms of how many people came in with an advance care plan.

We are also looking at the discharge process. On our discharge summary, the letter that goes to the local GP or specialist after hospital, so can we have a tick box for advance care planning? It is on our transfer documents but it is not on a discharge-to-home documents. That completes the loop by getting back to the GP, 'Yes, this patient has got an advance care plan now', and prompting that further discussion — or they commenced it or they need it followed up. We are trying to look at admission right through to discharge, and community as well.

Ms SPRINGLE — Earlier you mentioned a figure. You said 37 per cent of people who want to die at home are out of the catchment area and people coming in to support them through that, so that they would only get telephone support. Can you talk about what that actually means on the ground? I guess from the outset the idea that someone would be dying and only having telephone support and being alone is quite distressing to hear, so I would like to know a little bit more about the realities of that.

Ms JANES — The realities are if you are outside of the Warrnambool city, basically, or Allansford, so that is 8 kilometres or something, if you are outside of that area, the support we are able to provide within our service is: we visit — you will get a nurse support — and that visit is dependent on where you are in your treatment. So terminal, we would go every day, Monday to Friday. We may also link in with the local district nursing services around town and around the district. Then in terms of phone support, all our patients get a laminated sheet with instructions and the office phone number. So between 8 in the morning and 4.30 in the afternoon you get one of us, and then after that we put that phone through to Melbourne.

Dr GREENWOOD — To Caritas Christi.

Ms JANES — So if you are in Timboon and it is 6 o'clock on a Friday night and your mum has got pain, you ring 55 644 171 — —

Dr GREENWOOD — So a local number.

Ms JANES — So automatically behind-the-scenes it goes to Melbourne, and then they have a list of what we have done. They have access to our database, so they have got a list of what you have got in the home, what your diagnosis is and what your prognosis is. Then they would talk you through what you are ringing about. The data I have got there is actually what people have rung for assistance for, so the Caritas Christi data is around do they just want a symptom advice or did they — —

Ms SPRINGLE — Probably more what I am getting at is if somebody was really at the end-of-life stage and they want to be at home to die and they do not have support, because we are now finding that a lot of people do not have carers — —

Ms JANES — Yes.

Ms SPRINGLE — What does that look like? Is someone at home dying alone or with someone on the other end of the phone? Do you know what I am saying?

Ms JANES — Either that or it is not possible.

Dr GREENWOOD — And they have been an inpatient at their local hospital.

Ms SPRINGLE — So it is simply not an option for them to actually die at home, even though they want to?

Ms JANES — Yes. When we do not have carers involved, the nurses visit anyway, but when there is no carer the nurse would identify, ‘Okay, this patient wants to die at home. They do not have a carer. What other support do they have?’. If they are out at Timboon, ‘Hang on, this is not going to happen’. Hopefully if we get the referral early enough and we are tipped in, we would have that conversation early around, ‘We understand this is your wish. However, how are we going to do this? What can we do? Are we able to achieve it?’. Ninety-nine per cent of the time it would not happen.

Ms SPRINGLE — Okay. That is sort of where I was — —

Ms JANES — Unless you have family or carer support that can provide that care in a rural setting it would not happen.

Ms SPRINGLE — Thank you.

Mr MULINO — Going back to advance care planning, obviously with any regime you want it to be able to reflect people’s changing preferences. I am just curious: in practice do you find that people’s preferences do change very much over the course of their condition?

Dr GREENWOOD — Yes, they certainly can, especially since we are looking at this phase that we are going to start doing advance care planning for everyone. We are anticipating that it is something that has to be reviewed because people’s circumstances are going to change depending on what is happening with their health and just the process of ageing. So we do not have a set time that we would review an advance care plan after, but I would hope that we got into the habit of every time someone’s advance care plan, if it is an inpatient or there was a change in — —

I think the Have the Conversation plan says that every time there is a change in the person’s position, whether that be a new diagnosis, a diagnosis of a life-limiting illness or a change in doctor, their advance care plan is reviewed, and is this still in line with their stated wishes?

I do not know. Perhaps there does need to be something set — that they do become invalid after a certain period of time. But I think people do just have to be constantly vigilant that they are checking that they are contemporary wishes. Generally I look and see if it has been prepared within the last 12 months. I have to admit that every time I have a patient with an advance care plan, I read through it with them again for their new inpatient stay. I say, ‘This is what you stated three months ago. Is this still your wishes?’. But I do not know if everyone is doing that and whether we have to have something that enforces that or makes the advance care plan expire after a certain time so that that is forced upon people.

Mr MULINO — Would it be fair to say that, obviously, engaging with people is the first challenge?

Dr GREENWOOD — Yes.

Mr MULINO — Based on your experience, it is frequent enough that people change, but we also need to put emphasis on making sure that we keep them current.

Dr GREENWOOD — Yes.

Ms PATTEN — We have had a conversation about how we ensure that the advance care planning happens, and we have talked about whether it should be mandatory or somehow regulated in a way, or used in a mandatory part of measuring the services. Do you have any thoughts on whether we should be regulating or dictating how this is done?

Dr GREENWOOD — That is a very good question. How? No, I do not have any ideas on the ‘how’, I do not think, but I think yes, there should be something. But the ‘how’ I am not so sure on. I guess we are often asked as medical institutions to provide evidence to governing bodies of what we are doing, and I think that is what is happening. We have had the conversation, following the guidelines, collecting the data to support it and presenting that to appropriate authorities.

The CHAIR — We will have to leave it there, but to the four of you, thank you very much for your insightful evidence today and the particular perspective you can bring to us as a committee. We really appreciate what you had to say, and it has given us much food for thought as we deliberate and consider these important, challenging and difficult issues. Thank you very much.

Ms JANES — Thanks for having us.

Witnesses withdrew.