T R A N S C R I P T

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Geelong — 29 July 2015

Members

Mr Edward O'Donohue — Chair Ms Nina Springle — Deputy Chair Ms Margaret Fitzherbert Mr Cesar Melhem Mr Daniel Mulino Ms Fiona Patten Mrs Inga Peulich Ms Jaclyn Symes

Participating Members

Mr Gordon Rich-Phillips

<u>Staff</u>

Secretary: Ms Lilian Topic Research assistants: Ms Annemarie Burt and Ms Kim Martinow

Witnesses

Ms Jacqui White, Community Palliative Care Coordinator, Barwon Health;

Ms Joy Leggo, Chief Executive Officer,

Ms Lyn McCarter, Manager, Complete Care, and

Ms Karin Bauer, Community Services Manager, Multicultural Aged Care Services, Geelong; and

Ms Sue White, Chairperson, Hospice Foundation Geelong.

Necessary corrections to be notified to executive officer of committee

The CHAIR — I will declare open again the public hearing of the Legislative Council's legal and social issues committee in relation to the inquiry into end-of-life choices. I would like to welcome Ms Jacqui White, community palliative care coordinator, Barwon Health; Ms Sue White, the chair of Hospice Foundation Geelong; and Ms Karin Bauer, manager, community services, Ms Joy Leggo, chief executive officer, Ms Lyn McCarter, manager, complete care, Multicultural Aged Care Services, Geelong. Ladies, thank you very much for joining us.

Before we hear from you, I would like to 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 in the next week or so, and transcripts will ultimately be made public and posted on the committee's website.

We have allowed 45 minutes for the session this afternoon. Again, thank you very much for joining us here. We look forward to hearing your opening presentation, and thereafter the committee will have questions for you.

Visual presentation.

Ms J. WHITE — Thanks for the opportunity to appear today and to represent Barwon Health community palliative care. I wanted to quickly highlight just in terms of the first issue around medical practices supporting people in end-of-life care. I would like to highlight some issues around that that we have identified as a program and hopefully then quickly highlight some of the things we have achieved as well.

From a community palliative care perspective, we have identified four particular primary areas that we wanted to highlight that we feel create some challenges in supporting people to meet their stated wishes in relation to end-of-life care, particularly place of care and place of death. Things around respite care. That is, I guess, respite care in terms of both the in-home respite care but also inpatient respite care in the palliative care unit that you visited this morning but also within the residential aged-care facilities as well. It is about the availability of flexible support packages to support carers to care for patients at home, looking at an enhanced community palliative care provision and multidisciplinary capacity and ambulatory care.

Respite care. Supporting families and friends to provide care in the community requires us to be really flexible and really committed in our resources to provide timely breaks for carers. Respite care for us looks often like overnight inpatient care, day station inpatients — they respite overnight and so forth. So it is a really flexible and multifaceted mix of respite.

For us in Barwon Health, and I imagine probably quite similarly across the state, about 22 per cent of our clients actually do not have carers, which creates all sorts of challenges. If somebody does not have a carer, it actually makes it really difficult to support them to have their care at home. Most of those people also tell us that their preference is to have their end-of-life care at home, so then there is that sense of, 'How do we actually manage that if we have nobody there who is able to support them?'. We can go in and out, but we cannot be there obviously all the time. MACS will talk about their fantastic service and what they have been able to do, and that has improved our opportunities to support people in those situations markedly since the advent of that service. But it is a service that is supported by the Hospice Foundation. It does not attract any ongoing state or federal funding, so it is that sense of sustainability and how we do that. I think that is something for us that is really significant in terms of how we support those patients in that situation.

For our patients who do have carers, we have also looked at an audit fairly recently at what their needs are, and what that has demonstrated to us is that although there are a lot of similarities in carer needs across our population, they are not a homogenous group; they have really varied needs. So we need to be thinking about what sort of packages and what sort of care we can provide, and that is across a gamut. We need to be creative and we need to be innovative around that. It has to be flexible.

Part of trying to look at our flexibility is that we are looking at enhancing our hours of operation for our community palliative care program, acknowledging at the moment that a number of our carers are also in the paid workforce, so if we finish at 4.30, how do we actually engage with them? So looking at extending our hours and trying to think creatively about how we do that. That also allows us to be really proactive in terms of

supporting people coming out of acute settings if we have an urgent referral. If someone is urgently deteriorating at home, we can then manage them much easier as well with some extended time.

The other thing we are starting to look at is how we enhance our primarily nursing team — we are primarily a medical model with a very limited supportive care team — how we can actually enhance our supportive care provision and our allied health, because that is a huge challenge. Allied health and supportive care bring us a biopsychosocial model of care for people at end of life rather than a biomedical, so it is much broader; it supports people to be out of hospital and into home.

Just finally, our ambulatory care. One of the things we often experience in palliative care is late referrals for quite complex situations. Being able to engage with people in an ambulatory setting offers us benefits around being able to utilise our resources effectively and innovatively. We can provide a multidisciplinary response within an ambulatory care setting. We can introduce people very early on in their illness to palliative care, as a 'This is what we are able to do', and then we take a step back and engage as needs be.

We can provide continuity of care within that setting as well, so people being discharged from hospital may have met one of our physicians in hospital. We can then also engage with them in the ambulatory setting and can provide quite valuable resources to physicians caring for patients with multiple physical comorbidities.

Ms PATTEN — Can I just interrupt for a second? I am not quite sure of the term 'ambulatory care'.

Ms J. WHITE — Ambulatory — coming into a clinic setting. Essentially people who are able to come in and see us in clinic, we are able to offer them a multidisciplinary response there.

Ms PATTEN — Thank you.

Ms J. WHITE — One of the challenges, though, with ambulatory care is that it is not supported within the MBS funding or through our reporting mechanisms into the department, so there is a disincentive in some ways from that funding perspective.

Just really quickly in conclusion, I have talked about the challenges, but to highlight some of the positive things that we have been doing with that our palliative care setting. We have, despite the funding challenges, looked at enhancing our ambulatory care. We have also started to progress our extended hours within our current funding, and we have done some really amazing innovations within our supported care team, which is actually really small — there are four of us in supportive care. We are a world leader in dignity therapy, which is a validated therapeutic intervention that is looking at dignity in end-of-life care. It has come out of Harvey Chochinov's work in Canada. As an organisation, we have worked with our volunteers to actually ensure that we can offer that in as equitable a way as we can to the people who are approaching end of life. It allows them to leave a legacy document for family and friends. That has been a huge thing.

We have looked at how we utilise our volunteers around our bereavement program, so that we are actually meeting our bereavement support standards through the guidelines, and we have also developed a web-based toolkit for carers so that carers have access to information that is contemporaneous, that is accurate, that is clinician reviewed at any time.

The CHAIR — Thank you, Ms White. Does anyone else wish to make a contribution?

Ms McCARTER — Yes.

The CHAIR — Please.

Ms McCARTER — I will give you a brief overview of MACS and what we have done in relation to palliative care. At MACS we have community programs, we have a supported residential facility, which is a low-level facility, and an aged-care facility. Then we also have a palliative care program that we run in partnership with the Hospice Foundation, which funded the program. This has been an 18-month proposal/discussion/liaising with Barwon Health to see what was needed in our region and how we could implement that.

The care that we provide is in-home respite care and overnight care, and this is crucial for people in the community to keep them in their own homes. This reduces unnecessary hospital admissions when families can

no longer cope or they experience carer burnout. The Hospice Foundation has only limited funding, so it is not long term. It is quite short term, but it is making a difference in people's lives.

The palliative care team program has a team of personal carers who have specialised training in palliative care. The funding for the training is being provided by the Hospice Foundation to ensure that the team meets the skill set required to deliver end-of-life care. Our team of 12 personal care workers are flexible and can respond quickly to requests for care, and it is not unusual to only have a few hours notice to provide this care. The services provided include overnight care, in-home support and transport to appointments, et cetera.

In consultation with Barwon Health we have come up with five cohorts that we provide this palliative care for. They are people with a palliative diagnosis without a carer; support on discharge from an acute setting from either the palliative care unit or from a hospital setting; the CALD community, which is the culturally and linguistically diverse community, with a palliative diagnosis; people who are not able to access a bed in the palliative care unit; and respite for family members who are caring for someone with a palliative diagnosis. We do provide palliative care for anyone with a palliative diagnosis, even if they do not meet one of those five cohorts.

We do work closely with the palliative care team, and most of our referrals at this point are coming through the Barwon Health palliative care team. This program was launched in late February 2015, and to date we have provided care for 23 members of our community and have provided a total of 424 hours of in-home support.

The barriers we have to providing the care are funding clearly, because currently the program is funded by the Hospice Foundation Geelong and that is not an ongoing situation. It is just a couple of years that we can do that for, and we are hoping that we can get some statistics to get some government funding down the track. We do have some clients who have the capacity to pay for services, but they are in the minority; they are not the majority of people. Training is inadequate. It has been very difficult for us to source palliative care training in this region, and there was a lot of legwork that had to be done to get trainers to provide that care.

With the CALD community, historically cultural expectations are that family members provide the care. Cultural guilt: family members feel they have no choice other than to provide all the care for their loved ones for example, family members have withdrawn services at the last minute because of the loved one's wishes. And CALD communities are more reluctant to access support in comparison to the Anglo-Saxon community. Language barriers are also an issue, and culturally sensitive care, including religious considerations. Then there are the medications. It is currently not acceptable practice for personal care workers to give medications, and therefore the responsibility lies with the family member or a nurse is required to administer the medication. This puts extra strain on families or carers, because the idea of respite is to allow the carer to rest and prevent burnout. That is it, thank you.

The CHAIR — Thank you very much. Ms White, do you wish to make any comments about what the Hospice Foundation Geelong does?

Ms S. WHITE — What we do?

The CHAIR — Yes.

Ms S. WHITE — We originally were set up in about 1982 and we originally provided direct nursing care into the homes, and so hospice was quite unique for Geelong. The nursing staff went straight into the home through hospice care. But then in the mid-90s — 1999 is when the changes came around with government funding and so forth — we just were not able to sustain that. Barwon Health then took over the care, but during those times we were bequeathed quite a nice sum of money which we were quite fortunate about. We have got a board that is all volunteers, but we have maintained these grounds, and with the money that we make from the grounds we have been able to provide the community with hopefully a support in the palliative care role. MACS approached us, and we saw this as a way of going directly back into the community again, which is why it was set up in the first place. So we said to MACS that we will support them, and of course we had to make sure that Barwon Health was included, because that is the only way it is going to work.

So we are in a lovely situation where we can actually support them at the moment. But as it grows, which hopefully it will, we are not quite sure how long we can support it for. I guess we are looking back to the original time, too, when there was government funding as well. Certainly it is a wonderful situation because it

gives people that right of choice. They do not want to come to hospital; they want to stay home for as long they can. It has worked well for us too; it has been good.

The CHAIR — It is obviously a very productive partnership you have developed, and it is most important to hear what you are doing. If I could start the questions, I was interested in the points you made about staff training and how difficult that can be, and also the point you made about late referrals. We have heard a lot of evidence thus far about the need for more conversations in the community, so I wonder if you could perhaps flesh out those two points a bit more.

Ms McCARTER — Okay. With the funding, we met with Jacquie and we discussed that, because clearly all the carers have had training — they are trained personal care workers — but there is always a need for that bit more when we are talking about palliative care, so we wanted them to have a skill set that focused on palliative care. There was a lot of to-ing and fro-ing; it was not easy. We got the local TAFE to run a course for us, but it has not been an easy thing to access. We had to do a lot of negotiating, saying, 'This is what we want; this is what we do not want'. There is still more training that we feel needs to happen, especially in relation to communication, which is in the pipeline, but we wanted the program to be up and running.

We have only been operating for six months, and we wanted the program to be operating for six months before we do the next lot of training for staff, which will include communication — for them to be able to have those conversations with the clients they are looking after. If a carer already has a certificate III, there is no funding, so they have to pay. Currently it is \$650 to do the palliative care course, so that is quite costly if carers are expected to pay for it on their own. We were just fortunate that the Hospice Foundation saw it as a need for the carers to have that extra bit of training.

The CHAIR — Do you want to talk about the issue of late referrals as well?

Ms McCARTER — Yes. Most of our referrals come from Barwon Health. We have had this conversation. There are times when I know they are waiting for a bed. The nurse might visit a client, a patient, and then feel that they need to go into the palliative care unit, but there is no bed available, so they will ring and say, 'Lyn! This is one of those late ones; we need the referral'. They will give us all the information that we need to get, and then we will put in care to support the family and the person who is palliative. That might be overnight for one night. The most we have done — —

Ms BAUER — Three or four days.

Ms McCARTER — I think we have done three or four days in a row before a bed has been available for someone. That is what we have done in the past, which would usually mean that I have not been out to meet with the family or talk to them. It has come straight from the palliative care nurses, and then our referrals has gone from that perspective.

Ms PATTEN — Ms White, could you identify for me the cost of one of these patients going into a hospital bed versus enabling them to stay at home? I keep thinking that, obviously, it is — —

Ms J. WHITE — It is fairly markedly different, yes. I have not looked recently at the actual costings for a palliative care bed, but my recollection is that it is about \$7000 or thereabouts per day, and we are looking at nothing like that obviously. I have not costed out a community bed.

Ms McCARTER — I can tell you that if we put in an overnight stay, say on a Monday night, it is about \$500.

Ms J. WHITE — There is the financial cost but there is also the emotional cost that ends up in all of that as well.

Ms PATTEN — Yes, exactly.

Ms McCARTER — But in saying that, we can put in the overnight care. But if there is a family member there, and the person is needing their oral drops or whatever, we need to wake them.

Ms PATTEN — Yes.

Ms McCARTER — Or we need to call the palliative care nurse if there is not a family carer in the house.

Ms PATTEN — Is that a legislative thing or a regulatory thing?

Ms J. WHITE — It is a very grey area.

Ms McCARTER — Now let us crank up the soapbox, Jacqui!

Ms J. WHITE — It is a big can of worms. When we first started to have the conversation about working our service and MACS and the Hospice Foundation working together to develop this program, one of the things certainly from my years of practice, because I am a clinician as well, is that one of the hugest barriers for us in providing care for people right through their terminal phase at home is the issue about the delivery of medications — PRN medication, medication as needed. Certainly when we had introduced the idea of whether we could look at putting in an overnight carer to families, it was like. 'What is the point if you are going to have to wake me anyway to give the medication?'. So there were lots of barriers from the family's perspective in terms of accepting that sort of assistance.

One of the things we talked about and tried to explore — and I know Lyn and Karin got lots of advice around — was: is it actually a legal requirement or not? It seems a very grey area that we have not actually been able to get a clear perspective around.

Ms LEGGO — We sought legal advice, specialised legal advice, and it came back to us that it is a grey area and will probably need to be tested, but we would have to make sure that it was really clear and agreed with the family as to what we were doing, and all parties need to be in agreeance with the carer delivering the drops or whatever, and then specialised training would need to be given and some form of accredited course would need to be taken. But it was still considered to be quite a risk for an organisation to do it at a personal care level, when you are talking about someone with a base training of a certificate III with some specialised palliative care.

Ms FITZHERBERT — There are some drugs that would be potentially given to people during palliative care that were, say, morphine-based. Now they would need to be delivered by a nurse, would they not, in some categories?

Ms LEGGO — Families still can.

Ms J. WHITE — Families can be educated, and if they are willing they are able to give those medications, and we certainly have a range of mechanisms that we have in place in terms of our medical record so that families can record what they have given. Generally, though, those medications are drawn up by a nurse, labelled appropriately, stored appropriately in the home for that purpose, but we do need to have checks and balances. But generally, certainly from a paid carer's perspective, those medications essentially need to be given by a nurse.

Ms FITZHERBERT — I was interested in what you were saying earlier about the palliative care course that some people undertake, which I do not know anything about. Who tends to take that course? Would someone who was already a qualified nurse who was going into palliative care be likely to do that course, or is it for someone who is not necessarily coming from a trained nursing background but is going to be providing care and is looking to upgrade their skills in that way? I am curious to flesh that out.

Ms McCARTER — The program that we operate is purely with personal care workers, so we are not duplicating what Barwon Health provides, so it is predominately for personal care workers. It would not be something that a nurse would need to do, because they would have covered more than that in their nursing training.

Ms FITZHERBERT — That was my assumption.

Ms McCARTER — Yes.

Ms FITZHERBERT — What typically is entailed in that sort of training?

Ms McCARTER — It is for carers to actually be aware of what to look for as far as pain goes and for them to also be aware of their own values and beliefs — a bit of that emotional intelligence. It gives them a sense of

whether this is the kind of work that they really can do or not, and I think that is really important. We hand selected the staff that we offered this training to. It was not that anyone could do it. We actually did hand select the staff who we felt were going to be appropriate for this program. It is basic palliative care. It is pressure care. They are things that they would cover in their personal care course, but it just takes it to a different level, and a lot is on the communication side as well.

Ms SPRINGLE — I am just curious about the multicultural component of what you do, and what sort of cultural competence training your staff go through?

Ms LEGGO — As our name suggests, Multicultural Aged Care Services, our focus is on the multicultural community. Our cultural diversity report reveals we represent 40 different nationalities, so there is not one community client, one resident, we cannot speak to in their own language. We really value staff who have second, third or fourth languages. Every year we do mandatory education around cultural competency and cultural diversity. We do lots of lunch and learns where a staff member — at MACS we have 160 staff — will come in and talk about their culture and maybe bring in some food and share it with the staff and all those sorts of things. We are very in tune. One of our values is valuing the cultural diversity of our community, and that includes Anglo-Saxons. When we started 21 years ago, our focus was definitely on the migrant community, then post-World War II immigrants, the Europeans. But now multiculturalism has moved a lot in those 20 years, but it is all-encompassing and being welcoming.

The beauty of MACS is that we have this sort of invisible walls model of care, where people can come in at independent living, go to supported care, then go into residential and community packages as well, so they can go through the whole system. One of the things we have developed with Barwon Health and the Hospice Foundation is illustrated by one particular case where we had a lady who was on a palliative care package with the Hospice Foundation. Her condition improved so that we could not continue with the Hospice Foundation, but our community program was then able to step in, offer her a commonwealth-funded package, and we were able to keep that support. So we sort of have this lovely, seamless process happening, and we call it 'invisible walls'; people can move in and out of it as they need to. We think that is a model that can be replicated.

The CHAIR — Are you aware of that model existing elsewhere? Because in the health space generally we have heard other evidence that the system does not perhaps work as well as it could at different times, and what you have just described sounds very effective.

Ms LEGGO — We believe it is a model that could be taken in various other ways. We are a community not-for-profit organisation, and we think it is a model that could be picked up. Working with Barwon Health has been fantastic, but without the hospice we could not have done it. The reason we started it was that we saw a real need in the community, and people were wanting to remain at home and were not able to. We felt that we need to start talking to the hospice about being able to offer that. Lyn works with Karin in the community program, so they just dovetail together beautifully to make all of those packages and get good value for money for the taxpayer.

Ms BAUER — We recently expanded our packages to the western metropolitan region as well, and we have picked up 30 home care packages in that region, but we have found that some of the people we were looking after in the western region were not supported enough. For example, we had a Greek couple who were not able to get respite together in their region, so we were able to bring them to Multicultural Aged Care Services, because we do manage two respite beds as well. The outcome was really good for both the couple and the family. They had not had respite for three or four years, so it was a real struggle for this family to continue that care.

In relation to this invisible walls model that we have sort of evolved over time, we have never really had any issues with it. We have connected people back with their communities, people have made new friends when they have come in, so it is that come and go, and the fact that people are supported no matter what their needs are.

Ms LEGGO — From a palliative care viewpoint — and I have heard it mentioned about the interface between palliative care and residential aged care — I think in the broader community sometimes when people get to the palliative stage in a nursing home they are often sent back to the acute setting, but for us, no, this is their home. We need to care for them in their own home and allow them to die in their own home, which

happens to be our residential facility. Then we work with the palliative care team if we need to bring them in. I think that interface is really good as well.

Ms J. WHITE — Can I just comment too? Knowing the palliative care sector reasonably well, it is not a model that I have seen in other areas in terms of answering that initial question that you had. We have some great opportunities in Geelong in terms of our streamlined services. The palliative care program all sits under Barwon Health. We work then with the not-for-profit organisations. We support people to remain in their residential care facilities. We have that flexibility to transition people through the different sectors of Barwon Health in the same way that MACS is describing that through their service also, so I think it is quite unique in that sense.

The CHAIR — Do you think that is a product of the way the community comes together through the separate organisations and also because Barwon Health sits across the region?

Ms J. WHITE — I think it is the fact that Barwon Health sits across the region and that there is great communication and collaboration within the community sector as well. I think having the support of the hospice is part of that. We are unique in the sense that we have hospice's support also.

Ms S. WHITE — But there is a passion there as well, and I think that is why it works too. MACS certainly has that passion. I think that Geelong, even though it is a big city, still operates like a country town as well. Everyone works together like that and knows what is happening too. I think that makes it a bit easier.

Ms SYMES — I have a very practical question. Is there a standard example of a palliative care package?

Ms McCARTER — We have put in care for 23 people since February. No two lots of care have been the same. One of the examples is that we had a daughter caring for her mother. Her father was the primary carer. She had given up work and had arranged with her employer that she could work from home so she could provide the care. Then she was feeling threatened that she would lose her job so we arranged care for 4 hours a week so she could actually step into the office and keep her job security. That alleviated her stress levels of feeling that she might be unemployed when her mother did pass away and that she had nothing to go back to. That was one.

For other people it has been overnight care for some. For one woman we have on her own, we are actually taking her shopping and to pay her bills because there is no government-funded program that will do it how she needs it to be done. She can get the council for home care, but this service she cannot get and she does not have a home care package. So for this woman, this keeps her living in her own home and she has no-one else, so they are all very different and all unique.

Ms PATTEN — I just have a couple of quick questions. Just listening to those stories about what your palliative care package is, it almost seems like palliative care is not the right word for it. We heard earlier today that when people think 'palliative', they think the last part of dying. They have a very narrow idea of what it is. I want to hear your thoughts about broadening that term, because what you were talking about is something that is helping someone with their shopping and helping a daughter get to work — so many different things. It is not necessarily about making sure that the people's pillows are puffed and they are lying comfortably in their beds. Have you thought about that notion?

Ms J. WHITE — Certainly within our centre sector there have been lots and lots of debates nationally and internationally about 'palliative' and the names for it. I think the jury is out. I do think, though, that when I think about 'palliative' I always think of and have at the forefront of my mind the World Health Organisation's definition of what 'palliative' is, which is about the medical, the social, the psychological, all of those elements of somebody's care. It is not just that illness. They are that whole person who has all of these things going on, so if we can support elements of that, then we can actually help to enhance their quality of life for whatever time frames they have. That is where the flexibility that the packages that Lyn has described in the case examples gives you that real sense that we can think outside the square but emphasise that it is about the quality of life. But, yes, it is an ongoing debate about what is the correct name.

Ms LEGGO — We at MACS have a saying, 'If you come under our umbrella, it is not the end. There is still a lot of quality still to be had and it is our responsibility — —

Ms PATTEN — And experiences.

Ms LEGGO — Absolutely — and it is our experiences. For our core community it is about maybe connecting them back to their cultural communities or coming into our cultural activities and those sorts of things.

Ms PATTEN — We have also been talking about planning. In hearings last week we heard that with CALD community that can often be a difficult conversation. It is difficult to find the person to have that conversation and there are some cultural mores that might prevent that conversation. Has MACS thought about this sort of advance planning? Are you implementing it?

Ms LEGGO — Yes, we have trained advance care staff to be able to have that conversation. Yes, it is incredibly difficult sometimes, and sometimes families just simply do not want to know about it. My experience is about developing a relationship with someone and developing that trust, be it in their native language or be it someone else that they may trust because sometimes an Italian person may not necessarily want an Italian carer; they might develop a relationship with somebody else. So it is getting that connection and then those difficult conversations can be held and they may take quite some time. You cannot just expect to go in and do it and have it done in a couple of hours. It could take a number of — —

Ms BAUER — Sometimes 12 months.

Ms LEGGO — Absolutely. But then there have also been some times when it can be done absolutely beautifully. You know exactly for a Polish lady how important it is that you have gone out and bought all her new clothes and undies and everything. She has it all picked out ready to go and all those sorts of things. So it is having that cultural awareness. You were talking about how our cultural competencies are really important too — that that is the norm. When Polish people are dying, they love to eat. It is important to have all this sort of food that they would like to have, so making that available and all those sorts of things are really important.

We do have a lot of conversations around trying to have conversations, but with some people we just have to accept that the families do not want to know about it. They still say, 'I want Mum to go into hospital and have the drip' and all of those sorts of things. Then you have to step in and have other difficult conversations around that.

Ms J. WHITE — I think with advance care planning — and I know you met with Jill this morning — we have worked a lot with the Respecting Patient Choices team at Barwon Health to make sure that we give everybody the appropriate information so that they can make an informed decision. In terms of our client group, they come into our program where we are introducing the advance care program if they have not already got one or reintroducing it if they already have one for a review. So it has just become part of our normal practice to try to plan and have those. Sometimes people decline to do them, but at least they are making that informed decision about what they want to do.

The CHAIR — Ms Jacqui White, Ms Sue White, Ms Bauer, Ms Leggo and Ms McCarter, thank you very much for your evidence today and for informing this committee about this wonderful partnership the three of you have developed. It has been most informative. Thank you very much.

Witnesses withdrew.