THE HOUSE OF ASSEMBLY STANDING COMMITTEE ON COMMUNITY DEVELOPMENT MET AT HENTY HOUSE, LAUNCESTON ON WEDNESDAY 10 AUGUST 2016.

INQUIRY INTO PALLIATIVE CARE

Dr ROSEMARY RAMSAY, RURAL CLINICAL SCHOOL, SCHOOL OF MEDICINE, UTAS, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mrs Rylah) - Welcome, Rosemary. A committee hearing is a proceeding of parliament. This means it receives the protection of parliamentary privilege. This is an important legal protection that allows individuals giving evidence to a parliamentary committee to speak with complete freedom without the fear of being sued or questioned in any court or place out of parliament. It applies to ensure that parliament receives the very best information when conducting its inquiries. It is important to be aware that this protection is not accorded to you if statements that may be defamatory are repeated or referred to by you outside the confines of the parliamentary proceedings. This is a public hearing. Members of the public and journalists may be present and this means that your evidence may be reported. It is important that should you wish all or part of your evidence to be heard in private you must make this request and give an explanation prior to giving the relevant evidence.

Dr RAMSAY - I have written two submissions to the parliamentary inquiry into palliative care in Tasmania: firstly, on behalf of the Rural Clinical School in Burnie; secondly, as a general practitioner from those perspectives. They have been combined into one. I am employed as a palliative care specialist in north-west Tasmania for the THS, so I also wear a third hat but I am not speaking from that public servant perspective.

I believe the way a society or community cares for its young, disabled, elderly, frail and vulnerable is an important measure of the caring of society, so this inquiry is important to me and our community. Those who are ill and dying in our community deserve good care and I would define this as person-centred care. Another definition would be the right care at the right time and the right place. These are not new things, these are opinions that come from palliative care writing around the world. The rural people I serve in my general practice have poor health outcomes compared with many urban centres and places around Australia. The health literacy levels are poor. To me the cancer rate seems high, particularly the smoking-related cancers such as head and neck cancers and lung cancers. When I read the reports from my medical students' longitudinal cases, the presentations of cancer for these people who live out past Wynyard are late presentations and this affects their outcomes.

Chronic and non-malignant diseases are causing death and disability and are deserving of a palliative approach in general practice. Increasingly, as general practitioners, we are referring these patients for specialist palliative care. General practitioners in this area of Tasmania - the north-west - practise true cradle-to-grave medicine. Many GPs provide after-hours numbers for their patients and are available at any hour for their patients. In this area of the north-west I am speaking for, general practitioners also visit nursing homes at a higher rate than in some parts of urban Australia.

I see a great need across nursing homes in the north-west for building on the palliative approach that has been there for many years, but wearing my general practice hat I still see work to be done in the palliative approach. People in nursing homes deserve to die in that nursing home as much as people in their own homes. If you live in a nursing home, that is your home and you shouldn't have to be transferred to an acute facility in order to die. This doesn't occur that often but it still is occurring, and I think we could be providing more support for our nursing colleagues and GPs who provide nursing home care.

Specialist palliative care services support us as GPs but they provide what is called a consultative service so they do not take over from us as general practitioners. They support us with education and by being available on the telephone and they support us with the care of people that are more complex cases that we cannot care for as GPs.

Ms DAWKINS - You are in a fantastic position to give evidence to us because you are somebody in this rural and remote area who is at the coalface as a GP. We have heard over the last couple of days that GPs are absolutely instrumental in resolving the community issues that are perceived around palliative care. You have talked about the right tone, the right place and the right time to have that conversation, so what is the right time, tone and place to talk about advance care directives, for example, with a patient?

Dr RAMSAY - It was the right care, the right time and the right place. The question is around having those advanced care discussions and I would say it could be at any time in a person's lifetime. At the rural clinical school we teach the undergraduates in their fourth and fifth years that we could be having the discussion at any stage of our lives. When we are managing our general practice patients we might have a patient who is interested in that, so we have the skills to discuss it at that time. Key times would be a new diagnosis, entry to aged care, and at the 75 years and above health checks. In the general practice where I work we have care coordinating nurses who visit people at home when they have a new diagnosis and those nurses prompt us and remind us to renew the conversation.

Ms DAWKINS - Do most of your patients have a directive?

Dr RAMSAY - No.

Ms DAWKINS - What can we do to make that happen?

Dr RAMSAY - Our nursing colleagues are very key in the general practice, our practice nurses who do those 75 and above health checks. Simply having it in your practice software to prompt you is also a key thing and our care coordinating nurses also prompt us. We have to have some courage to have those conversations, particularly around dementia diagnosis. It takes time to grow as a doctor but one of my key learnings is that when you are diagnosed with dementia in my practice, you have this conversation and are provided with the documents to take home and read it, bring it back and ask questions.

Ms DAWKINS - My last question is around the legal framework for an advance care directive. Do you think it is important they have a legal framework?

Dr RAMSAY - Yes, however some of the important things we and families discuss are things you can do regarding wishes and beliefs and I am a strong believer in having those conversations in the family. That could mean you are having that conversation like this but it is the husband, wife and children around the kitchen table. Those conversations, particularly with our farming folk, resonate later in the years to come.

An example is my father-in-law, who developed dementia in a country town in Queensland. We had that conversation around the kitchen table. 'How would you feel if you were to have a lingering illness?', and he said things like, 'I can't stand this lingering' and expressed, as a farmer would, what he would expect. Later, when he is in a nursing home situation with advanced dementia and we have the choice of going back to hospital or not with a severe illness, we will be able to remember those words and remind ourselves when we are making those decisions. I think those discussions don't need fixed firm framework and most people make those really ethical decisions without the knowledge of a legal framework, and we should be encouraging those homely discussions.

Mr JAENSCH - You have referred to your fourth- and fifth-year students coming through the clinical school in Burnie. I would be interested to know from you what is their expectation or attitude to palliative care as part of their training to be a doctor?

Dr RAMSAY - We have done a qualitative study of this - one of the other doctors and myself and two of the students. They value the learning of palliative care, they value the multidisciplinary approach and they value the learning. In our survey which we are hoping to publish, students across the state - because we put our survey across the whole of the state - said that they felt there should be more teaching in palliative care, and this was from last year.

Mr JAENSCH - Do you go into attitudes towards care for people through the process of dying to ensure a good death, if you like? Are there ways of exploring that or is it about the care? We have picked up that there is some cultural shift needed in medical professions and I am wondering if that is a generational thing as much as a training issue, in particular where decisions are made with families or with the input from advance care directives to not provide treatment towards the end of life in an effort to provide the best possible quality of end of life. We have heard from some people that doctors are there to preserve life. Others believe there should be more of a focus around the person as they go through the end stages of life rather than on the treatment of illness.

Dr RAMSAY - The students say that they see palliative care as giving patient-centred care. I remember some students from last year saying that after they had been at the nursing home - all our students go to the nursing home for a week - that was where they first saw patient-centred care, person-centred care, and then they said at palliative care they also saw person-centred care. They had heard about it for many years but they had truly not seen it. I think we are seeing a generational change and I think that is because of the exposure to palliative care in their training. That is my opinion. Any other parts of your question that you would like me to elaborate on?

Mr JAENSCH - It sounds like there is some generational change happening and the training and exposure to different cases is coming with it. I wonder if government be considering how it intervenes to promote to the universities and colleges et cetera that there is a community expectation that we do end of life better, and if you think that is happening already with the next generation of physicians coming through then that is a good sign, a good trend.

Dr RAMSAY - Yes, and I think ensuring that it goes forward.

Mr JAENSCH - In 2010 or 2011 the Rural Clinical School was involved in a national pilot project for personally controlled electronic health records, the Cradle Coast Connected Care Project.

Dr RAMSAY - Yes.

Mr JAENSCH - Are you able to comment on that at all or anything we have learnt out of that that might be relevant to this inquiry?

Dr RAMSAY - Yes. I might go back to your previous question because I had a thought around general practitioners. From my understanding of many practitioners when they come to rural areas of the north-west, many of them are from other countries where there isn't any palliative care training. The specialist palliative care service as well as the mentoring of their GP supervisors would help those GPs know that palliative care is firmly entrenched in Tasmania. I think for those GPs strong mentoring by their supervisors as well as continuing exposure perhaps through the PEPA program and also a program called Decision Assist which has online learning regarding palliative care.

CHAIR - Professional development.

Dr RAMSAY - Yes, professional development. It is all available, it just needs to be accessed. As to your last question, I did take part in the review of the 4C project's e-health records. There were some strong learnings, and this is just from my memory, but the findings of the review of that program are freely available on the DHHS website. The five nursing homes that took up that education and were part of that program still have very much embedded positive parts of the palliative approach. Each use different parts but we did find that some nursing homes had strong advance care directives, others might have strong use of the 'traffic lights' where they were able to identify patients who were dying. There were strong learnings and positive learnings and the palliative approach was felt to need to be continued throughout those nursing homes. There are 1000 people living in nursing homes in our district.

Mr JAENSCH - Those project findings might be a document that is useful for us to follow up and capture.

CHAIR - I would like to go back to the directives. We have heard evidence that often at the time of writing their directive or creating it or even not writing it, people may have unrealistic expectations of what can be done. They also may have not heard what has been said by their GP or specialist or because of their lower literacy they might not be able to interpret what is actually being said. When we combine all those elements together - and this is evidence we received - there needs to be a conductor of the orchestra in this multidisciplinary approach to palliative care, including and ensuring that the family or group of supported people is also involved. Do you see the GP as the person best placed to do that? Secondly, if the relationship is not with the GP, who else do think should be that conductor?

Dr RAMSAY - In some ways you are asking about advance care directives but also around care of a person.

CHAIR - End of life, yes.

Dr RAMSAY - I would advocate for the GP to be that coordinator.

CHAIR - Yes, anybody else, any other role? Is there a nursing role in that?

Dr RAMSAY - Yes, the practice where I work has care-coordinating nurses and this is a new innovation built out of the Department of Veterans Affairs Care Coordinating Program. Our nurses who go out to see patients are very keen. I think because they are able to go to someone's home, a bit more ably. They have a car and they will go out and spend longer, they will explore the multiple carers that are available and different resources that are available for that person.

CHAIR - We have also received evidence from Hospice at Home. It sounds like a wonderful program that is working well. Is that available in the North-West and how does that fit into this model that you are talking about?

Dr RAMSAY - The Hospice at Home is part of the District Nurses in Tasmania and a non-government organisation. As a GP, my care-coordinating nurse would look at who could provide the type of care that my patient might need. So it might be community nurses, it might be Hospice at Home, it might include other non-government organisations that could put in place, say, housework or personal cares, meals, laundry services and such like.

They are part of a mix in our district and, I think, that for our palliative patients, the key nurses in our district are the community nurses, who are government nurses. I say that because they are community nurses with a strong education focus on palliative care, so they do syringe drivers, symptom management and care coordination.

Hospice at Home offers care coordination but it does not have those nurses who do the syringe drivers or the daily visits in our district. That is all done by the government community nurses. If there was someone with a complex dressing, from a cancer and a syringe driver, and symptoms that need reporting back to the GP, that is [done by] community nurses. Hospice at Home might do some personal care, some housework, some garden work coordination and provide some equipment if that's unavailable. Because they have tendered for some after-hours support, they would also put in some after-hours care as a phone number.

But then that might involve the GP as well. If it was my patient, they would also have my number, so patients would have the choice of the Hospice at Home number, which would go through GP Assist or coming back directly through to me.

CHAIR - It is a very complex picture for someone at the end of life.

Dr RAMSAY - It is. My patients often breathe a sigh of relief when I say that it will be coordinated through my practice nurse, and it will always be able to come back through to me.

CHAIR - Absolutely. I think when it goes wrong, is when we lose that central person.

Dr RAMSAY - And these practice nurses are part of our community. They have cups of tea with me, and can chat to me and say, 'I visited such and such, and they really need a visit. Could you go out on your way home?'. That is how it works.

Ms OGILVIE - I have a particular interest in end-of-life decision-making, but at the earlier stages of life, neonatal and paediatric, so I come at things from that perspective, being a mother as well.

I was really pleased to see in your submission the concept of the GP as the centre of what can be quite a complex puzzle - to me that makes a lot of sense. People know their GP, they are comfortable with their GP and can pick up the phone. There are often situations that are difficult to navigate. We have had some evidence given around complex family decision-making processes where not everybody is not on the same page at the same time. So it is that question in part that I would like to ask. Do you have experience of complex end-of-life decision-making situations where people haven't been on the same page and it has been difficult to navigate that? As a GP, what would your role be in trying to assist to reach a proper outcome? If you need to call on someone for advice or assistance or for ethical considerations, who would you call? How does that process unfold?

Dr RAMSAY - As a GP, if I had a complex family or a situation where there were perhaps different points of view and we are trying to make health decisions - perhaps for somebody without capacity - then I would listen and hear what people are saying, including - if it is someone in a nursing home - the nursing home staff, and try to coordinate a meeting. So practice nurses would be key in that because they might be able to do the phoning and gather people together, or it might involve the nursing home coordinating that. You would have to set aside time that probably is not well remunerated as a GP - there isn't really an item number for that.

Ms OGILVIE - Family conference.

Dr RAMSAY - Not quite, no. So if you couldn't resolve it by listening and your communication skills, then resources that you could use would be your specialist palliative-care colleagues. They would have nurses and doctors who could come to the meeting to help, or they may even coordinate a second meeting.

Now, if it was regarding a complex ethical issue, then as a GP I could involve my medicolegal -

Ms OGILVIE - You would have access to counsel?

Dr RAMSAY - Yes. Through the program I belong to I can ring and speak to a doctor. Also, if I involve my specialist palliative-care service, then they can access ethicists and other opinions from other colleagues within the health service in Tasmania. For example, if I rang my colleague in the specialist palliative-care service, then they could ring somebody in Hobart to have a chat. If it was a child, then that specialist service could consult with the paediatric service. If it was an even bigger problem, then we have free access to the Royal Children's' Hospital in Melbourne where there is an ethicist - Dr Jenny Hynson who has given us the ability to ring her.

Ms OGILVIE - Don't we have an ethicist at the Royal?

Dr RAMSAY - I am not sure, but I would seek them first.

Ms OGILVIE - Yes. I don't think we do, but you are closer to -

Dr RAMSAY - I do have a THS pack so I am a specialist palliative care doctor with the THS.

CHAIR - Unfortunately we are getting close to our time. Would you like to make some closing remarks?

Dr RAMSAY - In terms of the rural clinical school, we have a strong belief in the longitudinal education from entry into medical school right through until the fourth and fifth years where students go through the nursing home as well as through palliative care. I think from my GP perspective, I would be looking at the things we have spoken about regarding the building the GP skills through the PEPA program and mentoring Decision Assist education, encouraging GPs with a strength in palliative care to stay in the district. I guess my strongest point would be to advocate for the best care possible for our palliative patients in nursing homes, of which there are increasing numbers.

CHAIR - Thank you very much.

THE WITNESS WITHDREW.

Ms LYN IRWIN, FRIENDS OF NORTHERN HOSPICE, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Welcome to our hearing this morning. This committee hearing is a proceeding of parliament. That means it receives the protection of parliamentary privilege. This is an important legal protection that allows individuals giving evidence to a parliamentary committee to speak with complete freedom without the fear of being sued or questioned in any court or place out of the Parliament. It applies to ensure parliament receives the very best information when conducting inquiries. It is important to be aware that this protection is not accorded to you if statements that may be defamatory are repeated or referred to by you outside the confines of the parliamentary proceedings. This is a public hearing. Members of the public and journalists may be present and this means your evidence may be reported. It is important that should you wish all or part of your evidence to be heard in private, you must make this request and give an explanation prior to giving the relevant evidence.

Ms IRWIN - Thank you for the opportunity to speak with you. I am a registered nurse and recently elected chairman of Friends of Northern Hospice. We are an organisation with broad-based community support in the pursuit of reestablishing a dedicated ground-floor facility to provide end-of-life care for northern Tasmanians.

I would like to introduce some other members of our group who will support my overall presentation. Barbara Baker is a retired palliative care nurse, past chairman of the Friends of Northern Hospice and current director of the Northern Hospice and Palliative Care Foundation; Alison Andrews is a journalist and owner of the *Country Courier*, a northern midlands local newspaper; Mr Brian Walker is consumer advocate; Lyn Henty is a retired palliative care nurse, and joining us shortly will be the Reverend Alan Bulmer, an Anglican priest and chaplain at the Launceston General Hospital.

Whilst we do not wish to criticise or denigrate existing services in any way, we have concerns regarding deficiencies with palliative and end-of-life care provision in the north of the state. Unlike many other groups you have spoken with, we have no financial interest in the outcome of this inquiry. Our motivation is to advocate for the dying and the utilisation of a different model of care that has been found to be of so much value elsewhere.

For the purposes of our discussion it is necessary to be aware of the importance in distinguishing between palliative and end-of-life care. Palliative care as we see it is usually provided to a person with a life-limiting illness to improve their quality of life and should be offered as early as possible to prevent or treat symptoms of a disease and the side-effects of their treatment, along with psychosocial and spiritual needs. This can be provided over many months or years, so it is a long-term process. Whilst there is potential overlapping between palliative and end-of-life care such as symptom control and comfort care, end-of-life care is generally given when no further treatment is beneficial and death is close. That is the difference. End-of-life care looks at providing support for the patient, their carers and their family in a non-clinical home-like environment rather than an acute care setting.

This model of care is available at the Whittle Ward hospice in Hobart which provides end-of-life care for southern Tasmanians, as well as at Clare Holland House in the ACT, which I understand is run by Calvary as a public facility, and there are hospices in the Northern Territory and all other states of Australia. Hospices are a normal part of medical care overseas as well. This is even more important, we believe, when we know that Tasmanians have considerably higher than average incidences of life-limiting illnesses such as cancer. The Cancer Council advertisements at the moment are saying something like eight diagnoses of cancer are received by Tasmanians every day, which is exceptionally high. In Tasmania there are also higher than average incidences of heart disease, renal and lung disease, Huntington's and motor neurone disease, so all of these life-limiting illnesses are going to need end-of-life care.

From the most recent census statistics available we know that over 30 per cent of people 65 or over in the greater Launceston area are living alone and that approximately that same number again are potentially living with a frail aged spouse. That is over two-thirds of people in the greater Launceston area who may find it difficult to die at home, especially when full-time care is required. Thus, our attempt to establish a hospice in northern Tasmania is indeed a mainstream idea and consistent with best practice elsewhere.

With regard to advanced care directives, we consider this to be a reasonable tool to promote discussion on end of life and would support community-based initiatives to raise awareness of advantages for preparing such a document. However, there are many ways that advanced care directives can be promoted. For example, governments could send out information with pensions. Solicitors could be discussing it with their clients when they are there making the will. In fact there could just be advertisements to target the broader family unit to encourage discussion, similar to that which Rosemary was mentioning - the broader family unit, sitting around the table and discussing what the individual would require for end of life.

The obvious involvement for the patient has been with their GP, who is well placed to discuss and promote ACDs, given their close professional relationship. We were astonished and quite concerned to read in yesterday's *Examiner* that Ms Johnstone, the general manager of Palliative Care Tasmania - which until recently was known as the Tasmanian Association of Hospice and Palliative Care - has claimed that doctors have an outdated perception and do not really know how to talk about death and dying. We would be very interested to see evidence to support such a claim. Eminent Launceston physician Dr John Morris OA, MBE, dismisses Ms Johnstone's claims as total nonsense and Dr Don Rose, a well known Launceston GP, states that Tasmania as a 'forerunner in palliative care' - which was part of her quote - is almost delusional. When you have a broken health system like Tasmania, GPs pick up the pieces every day. I think that is a very fair comment.

Virtually every experienced GP discusses end-of-life issues with someone who has a terminal illness and often the family as well. GPs who conduct annual health assessments for those 75 or over, as we were talking about before, routinely discuss end-of-life wishes. In fact there is a particular section devoted to advance care directives on the generic form that is produced through Medical Director, which is the most used medical software program. That is actually already built into 75 years and over health care assessments. These are reviewed as circumstances change. This information should be accessible to all treating health professionals, and is now being made even easier with the establishment of the personally controlled electronic health records, the e-health records.

We certainly agree with Hospice at Home's Ms Onslow's assessment that an e-health record could streamline care. As she indicates, at least five or six different organisations are involved with the care of individual client, so should a crisis occur, carers are often confused as to which organisation to contact for assistance. If you have someone providing this, someone providing that and someone providing something else and there is a crisis, often at an ungodly hour, there are many phone calls to make, and as Rosemary says, more often than not you go through to GP

Assist who have no idea of your history or what you are talking about and they refer you off to something else. There is no real continuity there. A hospice as a centre of excellence would provide a central point for contact and provide support and direction to an appropriate service. Twenty-four hour availability should limit the need to resorting to call an ambulance, frequently resulting in admission to the emergency department.

Whilst surveys have shown that most people would prefer to die at home, we know that, most people are unable to achieve this in their final days. They may receive palliative care at home from a range of service providers for things like showering, meal provision or doing the shopping for you or whatever that might be. End-of-life care, however, requires 24-hours-a-day attention for perhaps days by more than one person. The relatives who have been caring for the dying person up to this point are often exhausted and frightened if it has been a long-term process. If suddenly there is a major change should a person's condition change rapidly, like increased pain or dyspnoea or something like that, and it is usually outside office hours, more often than not an ambulance is called and transportation to hospital occurs. This has happened on numerous occasions and is another reason why a dedicated end-of-life facility is necessary. People coming into the emergency department are subject to acute care medicine, as you would expect in an ED, so that is blood tests, IV scans or whatever. Really it is another reason for hospital cost blowouts and things like bed-block because these people should not be there in the first place. This is not appropriate for an emergency department. It is hardly an environment conducive to a comfortable, dignified death.

It must also be remembered that advance care directives are not legally binding in Tasmania, therefore no amount of public education and preparation of an ACD ensures that the wishes are implemented by the family, the nurses, the institutions and the doctors with regard to the person's own values, spiritual orientation and so on. So much is reliant on a good relationship and the family, the carers and the doctor. For this reason it might be better to encourage also having an enduring guardianship, a legal document lodged with the Guardianship Board of Tasmania that comes into effect only when the person does not have the capacity to make an informed decision regarding their preferred treatment. We welcome the opportunity to explain more of our hospice proposal as provided to you in the submission and any other areas of discussion and I thank you again for the opportunity to do so.

Ms DAWKINS - I am very interested in this specific situation with the bed-lock at the LGH which has been a very hot topic forever but especially in the last few months. Can you explain to me how that might work? Would the patient need to have made contact with the stand-alone facility prior to the crisis that might get them to the hospital?

Ms IRWIN - To go a step back, we see the palliative care service in northern Tasmania as having been very fragmented from the word go. It is quite siloed in that everyone is concerned for their own turf and that's about it. Ideally we would like to see the hospice facility as the central point from which these other services can emanate so that we are all on the same page. We know that Mrs Smith out there has a diagnosis of x, y and z, and that family are with her, or she lives alone, or she is estranged from her family or whatever it might be, so there is an idea of the family history. We come back to this central point. If there was a crisis, Mrs Smith can ring this central number at the hospice and if we can utilise e-health we can see that she is x, y and z and then be able to offer to - I am not explaining this very well. Can my team come and help me out, please?

CHAIR - No, they would have to be sworn in. You are doing well, go ahead.

Ms DAWKINS - This question has been a thread throughout the last couple of days. How would a paramedic be involved in this situation, somebody who has to give lifesaving treatment?

Ms IRWIN - Yes, it is a problem. In some ways this is where, if an e-health setup could be available to all medical caregivers, it would be easier to see that this person has an advance care directive which states that they do or do not want active treatment, they are palliative and are approaching end of life because there would have been interaction between the GP and the specialist palliative care unit and whatever else. To be able to access that information from central base, as it were, would certainly make it easier to be able to say, 'We know you are dying and do not need all the bells and whistles'. If you can come to this dedicated end-of-life facility where you can be seen as an individual who is nearing their end of life, then that is probably nicer than being zipped into the back of an ambulance and zipped off to hospital.

Ms DAWKINS - And potentially ramped.

Ms IRWIN - All that sort of thing.

Ms DAWKINS - You did touch on the legal frameworks for the advance care directives, do you think we can have a conversation about that legal framework without talking about voluntary assisted dying?

Ms IRWIN - I think that because the basis for our argument is that it is a choice for the individual, that the individual should have the say for the treatment they receive and how their life/death goes, as contentious as it is, that perhaps - I am not advocating it per se, but I am saying that perhaps it does need to be incorporated in the broad discussion for end of life. So not necessarily the taking of one's life but rather the degree of medical intervention that there is, which may not necessarily preserve that life for an unnecessary length of time.

Ms DAWKINS - Thank you. I know it is a complex problem. From my point of view, if we are going to take it into that arena where we are speaking of it from a legal perspective it is hard to talk about the legal framework without going to that step, yes. We have had a variety of answers on that, so thank you.

CHAIR - I think it is important that we stay within the terms of reference of the inquiry, which is into palliative care. The other comment I would like to make is that without swearing in your supporters and colleagues, they may whisper in your ear and then you can speak if you are wanting guidance or assistance from them.

Ms IRWIN - Thank you very much. I have been thrown in the deep end, yes.

Ms OGILVIE - You are doing very well. Thank you so much for coming. I am aware of the work that you are all doing. I have recently had the benefit of visiting jurisdictions across Europe, looking at different models of care from the Levenseindekliniek Clinic in the Netherlands which is actually an end of life clinic - it goes beyond their ceasing treatment and the palliative approach - right through to the Irish Hospice Foundation, who I have met with and spoken to at length. I have a great degree of love for Calvary Hospital, who saved me when I had my own particular circumstance of a dying child. I couldn't go home and I was in a maternity ward with the happy mums. So, for me having a safe space to go to was absolutely critical. If not for Calvary, I would have had a much worse journey.

So I very much hear you on hospice. I am keen to see choice provided but to also put out there for comment that death and dying happens right across the age spectrum. It is not just about older people. I am in the zone where friends of mine have had children die and I have actually experienced that as well, so the complexity around that is quite robust.

If I could wave a magic wand and say we have funding for whatever we want, I would say a hospice in Hobart would be great too. The Whittle Ward that you have mentioned - I am not sure if you have visited the Whittle Ward?

Ms IRWIN - Yes.

Ms OGILVIE - My personal reaction to that is that I would describe that more as a hospital setting. I don't think you could call that hospice. So when south filled, like here in the north, that space in that sense is not filled So with all of that preamble, are you on the trajectory to establish what would effectively be a private institute under a charitable foundation? Is it something that you feel can be managed by the community with fundraising? Or are you really proposing that it should be part of public health provision? I am sure you have some thoughts about that - it comes to the money - and what are your views on that?

Ms IRWIN - Certainly it does come to the money. I think our difficulty is certainly not the building of a facility. There would be no problem from community support, definitely, to raise funds in order to establish and independent place, maybe out in the country with lovely gardens and verandas, out in the sunshine, all of that sort of thing. There is no concern with that at all. Our concern is the actual running of it. It would need to come from government, I think, or a private health fund or something like that would need to provide staff.

Ms OGILVIE - It is the operational costs, which would be -

Ms IRWIN - Which is why, in our submission, we attempted to give the Government a gift on a platter by suggesting that Allambie, which is an already established building, could be renovated. Because there is palliative care there already, coming back to the all operating out of the one centre.

For instance, Colac Hospital in Victoria is a total community hospice. They have programs whereby the local abattoir owner is so taken with the hospice model, that he provides funding for the staff. They have an annual gala ball, which this year raised over $200 000, just from auctions and what not. That goes to maintenance. They have a different model. Theirs is a voluntary thing, and it is only Monday to Friday. It is a little more 'respitey'.

Ms OGILVIE - There would be a great diversity of services.

Ms IRWIN - Yes, there is.

Ms OGILVIE - Respite is good too.

Ms IRWIN - Again, if you are looking at palliative long-term caring at home, carers do need respite. When we had Philip Oakden, a client could come in for symptom control or something like that, and then was able to go back home, and die, peacefully at home. That gave the carer just that opportunity to recharge, the patient to come back to a manageable level, and then die in an environment in which they wish to die. We do believe that needs to be accessible to everyone. I think that is the key with what we have at the moment, is that it is a little bit higgledy-piggledy, public and private. The government does fund the 10 beds in the Whittle Ward. Yes, I agree with you that perhaps it is not an ideal location, but it is what there is, and it has ten public beds. That services the whole of the south of the state.

Ms OGILVIE - And what are you saying in the north?

Ms IRWIN - In the north there are four publicly funded beds. They exist in the Melwood Unit in Calvary. The rest are private beds.

Ms OGILVIE - Do you have an idea of the total?

Ms IRWIN - I think the total is about 15.

Ms OGILVIE - Fifteen in the north? So that would be insurance payments to -

Ms IRWIN - Yes, they are private, so you need to be insured to be able to access those.

Ms OGILVIE - So there is a gap of six public beds?

Ms IRWIN - Yes.

Ms OGILVIE - Thank you, that is helpful.

Ms IRWIN - Yes. At the moment, therefore, dying patients are being cared for in the Launceston Hospital.

Mr JAENSCH - I am interested in the distinction that you have made quite deliberately, in distinguishing between palliative care and end-of-life care, and the critical difference there. As I understand your reading of it, palliative care is the taking care of someone at home or in the nursing home, possibly, through their decline versus end-of-life care where it is -

Ms IRWIN - It is to give the best quality of life - with a terminal diagnosis. It is to give overall support to -

Mr JAENSCH - Yes, you have made a distinction between palliative care and hospice care, I think. You have drawn a line somewhere there separating different stages.

Ms IRWIN - Yes, palliative care is long term; end-of-life care is within the last hours or maybe days of life.

Mr JAENSCH - Are you proposing that hospice setting for the end of life -

Ms IRWIN -Is a preferable model because you are not going to end up in an acute accident and emergency unit or in a multistorey 'clinical' environment. It is to provide a more home-like, non-clinical area where, as an individual, you can have whatever environment is right for you as far as family and friends and pets and access to -

Mr JAENSCH - But different to being at home because it needs to have certain trained people, and facilities on hand. Is that right? It isn't quite hospital but it has got to have clinical capability, I think, is the inference.

Ms IRWIN - It does need to have a clinical governance, yes.

Ms OGILVIE - But it addresses the loneliness - the 'alone problem' which is a very human.

Ms IRWIN - And very prominent in this area

CHAIR - Lyn, would you like to make a concluding statement?

Ms IRWIN - We believe that a dedicated end-of-life care facility, providing a home-like, non-clinical environment is a preferable model of care for Tasmania, as it is in every other state and territory of Australia and, indeed, overseas.

CHAIR - Thank you very much.

THE WITNESS WITHDREW.

Ms ALLISON CAMPBELL, Mr GRANT MUSGRAVE AND **Ms SARAH SEXTON,** CALVARY HEALTH CARE TASMANIA, ST LUKE'S HOSPITAL, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR - Thank you for your attendance here today. A committee hearing is a proceeding in Parliament. This means it receives the protection of parliamentary privilege, an important legal protection that allows individuals giving evidence to a parliamentary committee to speak with complete freedom without the fear of being sued or questioned in any court or place out of Parliament. It applies to ensure that parliament receives the very best information when conducting its inquiries. It is important to be aware that this protection is not accorded to you if statements that may be defamatory are repeated or referred to by you outside the confines of these parliamentary proceedings. This is a public hearing. Members of the public and journalists may be present and this means your evidence may be reported. It is important that should you wish all or part of your evidence to be heard in private you must make this request and give an explanation prior to giving the relevant evidence.

Mr MUSGRAVE - Calvary St Luke's Hospital has been providing a palliative care service to the community of northern Tasmania since 2006. In 2007 the service was expanded to include public patients. Today the Melwood Unit is a 15-bed inpatient specialist palliative care service providing an excellent service to our community. As a dedicated palliative care unit we utilise a collaborative interdisciplinary team approach to achieve comprehensive patient-focused outcomes to our patients, their carers and families.

Spiritual care is an essential component of the Melwood Unit's holistic approach for both patients and families regardless of their spiritual or religious beliefs. Support is provided by Calvary's highly experienced pastoral care team as well as other community services who are able to care for specific spiritual needs. We work closely with the community-based team reviewing each patient individually and ensuring all patients' health care needs are integrated and addressed on an ongoing basis. This allows a seamless transition from hospital to home and vice versa.

Our aim is to provide the highest standard of holistic care to all people regardless of socioeconomic status, age, gender, sexual preference, race, religion, disability or politics. Our values of hospitality and healing stem from respect for human life and the care we provide to all people as they approach their end of life. We believe that dying is an experience unique to each person, family and carer because everyone is different and their responses to illness and treatment vary. Our services are tailored to meet each individual's needs. We are extremely proud of the service we offer to our community.

Ms DAWKINS - If there was a stand-alone hospice facility, would you continue to offer palliative care as one of your core services?

Mr MUSGRAVE - I guess if there was, for example, a 10-bed hospice - we currently run a 15-bed service - it would diminish the number of palliative care beds we could offer so we would have to run that in conjunction with a medical ward; in other words, you could have a small component of palliative care within a medical ward. You couldn't have a dedicated specialist palliative care service in my view, but I am not sure whether my colleagues agree.

Ms DAWKINS - There is some flexibility, isn't there, around that bed mix. I know you have four public beds but should you have all of those beds full and somebody needs palliation, is there something in place to be able to allow them to use the other beds?

Mr MUSGRAVE - Absolutely. On occasions we have nine public patients within our facility so we flex up and down as the need requires.

Ms SEXTON - We meet every three months with our contractor and discuss where we are sitting with percentage and we have had assurance from DHHS that if we do need to go over, provided it is a doctor approval that this person does not need palliative care, they will approve it.

Ms DAWKINS - My last question is around religion. If a committed atheist came in for palliative care, what sort of style would you adopt with managing their care?

Ms SEXTON - We don't really change it depending on what religion you are; pastoral care is offered to everyone, no matter what religious denomination you are.

Ms DAWKINS - You have said that spiritual care is an essential component.

Ms SEXTON - It is if you require it. We do it individually, so if you don't want spiritual care we're not going to force it upon a patient. It is what they would like, so we do it on an individual basis. If you came in and wanted some religious care then certainly we would implement that but if you do not, we respect that and would not force it upon you. The pastoral care team are wonderful in that they don't necessarily go in and start talking about religion. They talk about other things that may then bring out what people want.

Ms DAWKINS - Thank you very much.

Mr JAENSCH - Spiritual care does not necessarily need to be religious either; there are other forms of meditation and other counselling. I am interested in the flexible arrangement that you alluded to before where you have four public beds but you have a rolling arrangement with the department that if there is demand you can expand those into other beds. Where is your overflow? How do you manage occupancy in 15 beds? If you have the ability with public patients to go to from four to nine, where do you drop out five to make that happen?

Ms CAMPBELL - We have the capacity to absorb some of the patients who might have been put into those beds in other parts of the hospital, so that allows us to have that degree of flex.

Ms SEXTON - We haven't really had a lot of need. We find 15 beds really does cater for what is needed the majority of the time. We have that ability if we needed to where we would as soon as possible bring that patient back to the unit, but it is very unusual that we have to. Unless it is a doctor's wish to put them on a different ward we don't tend to have to do that.

Mr MUSGRAVE - We have another medical ward where we can expand our capacity but as capacity but, as Sarah says, it is very rare.

Mr JAENSCH - That would be for a period of need. Would any patients who were not able to be catered for in your Melwood ward be relocated temporarily into another capacity in the hospital and then back in?

Ms SEXTON - Yes, and our palliative care doctors would go and visit them in that area and pastoral care and social work would still be involved even if they are not actually physically on our unit.

Mr JAENSCH - They just don't get the soft furnishings and a view of the garden.

Ms SEXTON - Yes, and the mountains.

Ms OGILVIE - On the issue of multicultural and other affairs, I am the shadow minister and I believe Calvary does the spiritual aspects of that pretty well; I think I might have seen a brochure before. Could you sketch out for me from that perspective how you handle the diversity - I have seen it in the south and I am sure it is similar in the north - for someone perhaps from a Sudanese background and how you manage those issues?

Ms SEXTON - About six months ago we had a Bhutanese family member. I will have to think what organisation it was that was done in conjunction with, but they had a representative with them and we worked a lot with them because of the language difference. There was a large group of them and they had a spokesperson from the Bhutanese community who spoke very good English so we did do a lot of liaising with him to be able to meet their needs.

Ms OGILVIE - It is my understanding that you do that quite well, and it was reflecting on Andrea's question on what spiritual looks like.

Ms SEXTON - I really enjoy it when we get someone like that because you learn a lot from that sort of thing.

Ms OGILVIE - There are great stories that come out of all of these experiences. I am certainly grateful I was able to baptise my baby, for example, which was my thing.

More to the technical process side of things now. If you have a complex end-of-life decision-making situation, whether it is family complexity or medical complexity or complexity around competency, what is your escalation path and do you have access to ethicists because you are a large national organisation? How do those structures work?

Mr MUSGRAVE - We have an ethics committee that is based in Hobart. We can go through our local ethics committee -

Ms OGILVIE - Do you have immediate access?

Ms CAMPBELL - Yes, I am actually on the committee.

Mr MUSGRAVE - If we need further help we can certainly escalate it to the archbishop or higher than that. We can go through our national system as well.

Ms OGILVIE - So you have layers of assistance you can draw upon.

Mr MUSGRAVE - Correct.

Ms CAMPBELL - It is not just Catholic assistance but people from other belief systems to assist with the diversity of knowledge and experience is also present in our pastoral care team within the hospital. They come from different backgrounds; they are not all Catholics, so they have a good understanding of spirituality.

Ms OGILVIE - So you are saying there is diversity.

Ms CAMPBELL - There is, of experience, knowledge and skills, and that adds to the quality of the offering for people, because they have some understanding of spirituality that is far broader than just a catholic perspective. Although obviously that is our area of expertise, we can accommodate people from all belief systems, and certainly also for those without any beliefs, as you mentioned.

CHAIR - Thank you. We heard earlier in evidence the implication that in the northern area - the old 003 area, I am guessing - we have an economic driver and a demographic driver, that implies there is a very large need for additional palliative care and end-of-life care in this region. However, you have said that your beds meet the need that is out there. Can you give us a context to those two statements? Do you get overflow? What happens when there are problems at the LGH and perhaps beds are not accessible. Does it flow through to St Luke's? How does that work?

Mr MUSGRAVE - I guess on very few occasions do we overflow over the 15 beds, but there are other palliative care beds within the regional communities. For example, at Scottsdale and Campbell Town, there are palliative care beds so it is not just the four public beds that are isolated to Calvary, there are other regional beds, as I understand it. It is not just the 15 plus Scottsdale, Campbell Town and Deloraine, where people can access those services as well. We have the 15-bed unit, but if there are capacity issues we can overflow to our medical ward to accommodate those patients.

CHAIR - If there is a lot of demand on the LGH do they refer clients, or are patients sent to you? How does the system work?

Ms SEXTON - Do you mean just palliative patients?

CHAIR - Yes, palliative or end-of-life patients.

Ms SEXTON - The process is that the community palliative care team have staff in the LGH who review the patients and when they assess them and think they are ready for Melwood, they will ring and get a bed there.

CHAIR - Right. So if they have come into the emergency unit at the LGH, what happens? Is that the same process?

Ms SEXTON - Yes, they would contact the public care team who will go and review them in the emergency department and bring them across. The other thing is when the patients have been with us and are known to Palliative Care they are given a number so during the day they can contact Palliative Care and after hours they can contact Hospice at Home who can then contact the doctor and avoid them going to the ED. If they are known to the service quite often they don't go to the ED, they will come straight to us.

CHAIR - And do you see that that process works well or are there issues? Could you give us some sense of that?

Ms SEXTON - I think it is a shame that the community public care team's after-hours service shut down a few months ago now and I would really like to see that up and running again. I think that is really important because they know the patients to a greater degree than the Hospice at Home people so I think it would be wonderful if they could have an after-hours service again.

CHAIR - We heard evidence earlier that often with the elderly and the people caring for them, if a crisis happens they are often out of hours and in fact in becomes a crisis because it is out of hours, so an after-hours service seems sensible.

Ms SEXTON - The other thing is that we work in conjunction with the community palliative care team, Hospice at Home and community nursing and we meet twice a week and discuss patients within the unit and patients in the community, so we know what is out in the community as well as what is hospital based.

Mr JAENSCH - So are you then looking at people who may be receiving support and care in their home who later progress to being admitted?

Ms SEXTON - Absolutely. The doctors and the community palliative care team are aware of who in the community may have upcoming needs coming in. Sometimes it is an emergency but sometimes they know that the carers are definitely getting tired, so we have booked admissions but we also do on a day-to-day basis what is needed with the community. We look at what is in the community and what is in the LGH and if a patient was being cared for in the LGH and there was one struggling in the community we would take the community patient first who has higher needs than someone who has been having their needs met at the LGH.

Mr JAENSCH - Yes. You are reflecting similarly as to our last witness where there is a distinction between the care that someone can be offered in a home or nursing home environment that is not specially set up and they can be supported there, but then they progress to a higher end-of-life care phase.

Ms SEXTON - We have lots of people we let go home and who die at home, but as we have said, sometimes the families can't cope and they do need to come in.

Mr JAENSCH - Yes, or there is no family.

Ms SEXTON - There might be no family or they are just physically exhausted or emotionally they can't cope. It is very difficult to look after someone at home.

Mr JAENSCH - There is a spectrum of circumstances we can identify and the person's nature of their illness and the circumstances of the family are very individual.

Ms SEXTON - Absolutely.

Mr JAENSCH - Can you identify within the spectrum of need where there is maybe a gap now?

Ms SEXTON - Personally I feel that we need more trained staff in the community so people who do want to die at home can do so. There is a lot of evidence in other countries that music -

Mr JAENSCH - Sorry, are you referring to trained volunteers or more to the nursing workers?

Ms SEXTON - Nursing staff.

Mr MUSGRAVE - We know that in New Zealand, the USA and France a lot more people die at home than in Australia. I think only about 14 per cent of the people in Australia die at home. So there is a need for better education and better community services to enable the number of Australians dying at home to increase.

CHAIR - Would you say that that is the greatest need? If we are trying to rank these needs in priority order, where does that sit from your perspective?

Mr MUSGRAVE - I think most people would like to die at home, as I understand it, so there is a pretty high need. In terms of ranking, I guess it would be up there.

CHAIR - It's a high priority.

Ms OGILVIE - On a similar vein, I have conversations amongst my peer group, many of whom are living interstate, and we had a chat about this challenge. Recently my brother-in-law came down and had to spend a lot of money on accommodation when his mother was dying, an uncertain time frame, and it was an incredibly difficult situation. We have a generation of children who left - it's a bit like Ireland. What do we do to help older people whose family are interstate, who might come home. How do we manage that better? Is that something we should be thinking about?

Ms CAMPBELL - Certainly it is an area that needs enormous resourcing. It is very, very resource hungry. People's homes are not set up like palliative care wards. They don't have the right beds, they don't have the right equipment and they may not have facilities downstairs for toileting. If they are obese - and we all know about obesity in the community - that just makes everything triply difficult; to have the right equipment that is weight-tested, weight-rated and has all the capacity that will not put that person in danger. The wrong equipment can make for very poor outcomes for people. I think that is perhaps an area that if we are considering how to help people to have their wish of dying at home it really has to be resourced enormously.

I had the experience of trying to help my mother to die at home a couple of years ago in Scotland. In the end, it wasn't feasible not because everyone wasn't willing - everyone was - but physically and emotionally, it is very demanding for people. Relatives often cannot go the distance. That is when we get them in Melwood. The wonderful thing then is that you have this multi-disciplinary, inter-disciplinary team of people who can come in, and pick up the family who are often so exhausted and so stressed. The social worker can assist them with all sorts of financial questions. I think that is all very hard to replicate in the home. Those issues percolate to the top and often become 'the thing' that people remember about the death.

Ms OGILVIE - Very practical.

Ms SEXTON - I did also look after my brother-in-law at home about a year-and-a-half ago. He was in his fifties and I would agree.

Ms DAWKINS - It's intense.

Ms SEXTON - I was lucky that I had the training behind me that I could provide that care, but I had to outsource from my sister's friends to get me equipment. It was over a weekend, once again. We are lacking in the community, more than anything.

Ms DAWKINS - We know that the core business of the LGH is people who are dying, can you speak to the anecdotal evidence that there are many elderly people dying in the LGH that could be freed up for acute cases instead?

Ms SEXTON - You may be asking the wrong people.

Ms DAWKINS - It is something that we anecdotally know. It wasn't reflected in the last feasibility study.

Mr JAENSCH - You can't anecdotally know things.

Ms DAWKINS - Obviously, we hear that the LGH is blocked with elderly people. If the system is working -

Ms SEXTON - But are they blocked with elderly people waiting to go into nursing homes?

Ms DAWKINS - That's the question we don't know.

Ms SEXTON - They are not actually palliative. I think a lot of it is we are getting an older generation of people. It does get bed-blocked with people waiting for nursing-home placement. I can't tell you that that definitely because I have not seen the evidence for it, but I think it is going to become a bigger problem.

Ms DAWKINS - Yes, that is what we understand. So you think that there is that one step in between somebody being admitted to the LGH, going into an aged-care facility and then perhaps going into a palliative care facility or being palliated in the aged-care facility itself.

Ms SEXTON - It depends what their needs are when they actually there, but, yes.

Mr MUSGRAVE - We have a system in place where our bed coordinators speak daily with the LGH, so we help them out on a daily basis as it is required. I suppose that is part of palliative care, and it is in other areas as well. We certainly try to help them to the best of our ability if we have the capacity and the staff to do it. That is a daily process, unless they haven't got the need to seek assistance from us.

Ms SEXTON - You are allowed to bring your animal into visit.

Ms DAWKINS - Yes, I saw that; it is very good.

CHAIR - Would you like to make a closing statement?

Ms SEXTON - I am very proud of the work we do at the unit. I think it is very multidisciplinary focused; we get good outcomes and we get a lot of very positive feedback. I think there is that misconception that you are in a hospital and you are going to get IVs and things like that that we don't do. We don't put IVs in for end-of-life care; we don't send people for X-rays; we don't do any of those medical treatments that I think a lot of the community are worried will happen. We take a palliative approach, definitely, and the doctors certainly don't do any unnecessary testing while the patient is there.

CHAIR - Thank you very much. It has been really very valuable to understand the different perspectives. Your perspective today has most helpful in understanding what is happening here in the north of the state and [appreciating] the close integration you have with the LGH and all the care-givers in this complex area of health that we are inquiring into. It is greatly appreciated.

THE WITNESSES WITHDREW.

Ms LOIS BERRY, MANAGER, AND **Ms JANICE LIPSCOMBE**, SECRETARY, HOSPICE CARE ASSOCIATION OF NORTH WEST TASMANIA INC, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR (Mrs Rylah) - Welcome. A committee hearing is a proceeding of parliament. This means it receives the protection of parliamentary privilege. This is an important legal protection that allows individuals giving evidence to a parliamentary committee to speak with complete freedom without the fear of being sued or questioned in any court or place out of parliament. It applies to ensure that parliament receives the very best information when conducting its inquiries. It is important to be aware that this protection is not accorded to you if statements that may be defamatory are repeated or referred to by you outside the confines of the parliamentary proceedings. This is a public hearing. Members of the public and journalists may be present and this means that your evidence may be reported. It is important that should you wish all or part of your evidence to be heard in private you must make this request and give an explanation prior to giving the relevant evidence.

Ms BERRY - I am the manager of Hospice Care Association of North West Tasmania Inc. I manage the volunteers.

Ms LIPSCOMBE - I am the current secretary of the board of management of Hospice North West. I probably should disclose that I am also a nurse on the north-west coast.

CHAIR - Thank you. Would either or both of you like to make an opening statement?

Ms BERRY - I have not really thought much about this but it is really a submission around what I have learned so far in my role as a manager for volunteers and how we fit into all the other services around us on the north-west coast. That is the premise of where I am coming from.

Ms DAWKINS - We have heard from a couple of speakers over the last couple of days about the importance of the social networks and volunteers embedded in the community, people who do not get paid but who have a natural understanding of the requirements for their community members. You are already doing it, so for that we are really grateful. How could you be best supported to continue in this role?

Ms BERRY - To actually manage the service we have, in a lot of ways we are quite well supported financially from the state government so that we can assist with -

Mr JAENSCH - I will write that down and put it in a speech.

Laughter.

Ms OGILVIE - That's the first time we've heard that in the last three days.

Ms LIPSCOMBE - I fully support that answer because we have the funds to provide the service we provide, which is volunteer assistance in the social perspective for our end-of-life clients. Our needs are around the infrastructure around us to support our clients.

Ms DAWKINS - When you say 'infrastructure around', do you mean the intersection of all of the different organisations you work with to support your people?

Ms LIPSCOMBE - Yes. On the north-west coast all palliative clients are managed in the community and some have to come to hospital infrequently or at end of life because we don't have a safe place to put them for transitions in their care. Our service is rather concerned about that process because we can't guarantee privacy or the right - there are facilities within all the health establishments to accommodate palliative patients but they are not dedicated beds and with our current focus on infection control in Australia I am losing more and more single rooms in hospital settings that once we could protect for palliative patients. Without dedicated beds from a hospice perspective we may have to recommend to the nursing service that we would be better off to put this patient in a safe place at the moment, and when the patient proceeds to hospital there is this huge level of uncertainty - 'Will I be in a four bed ward with screaming mixed people? Will I be in a nice quiet area where I can continue my journey?' - and that is creating anxiety for all service providers.

Ms DAWKINS - Would you say that a stand-alone facility is essential as a part of the suite for care?

Ms LIPSCOMBE - That would be the dream. I would be really happy with short steps along the way to prove that, and protected beds initially and consumer feedback around how best the needs are met and then upping the ante as the community drive it. I do believe in having a stand-alone hospice but I also have trouble seeing a community like the north-west getting there in a hurry.

Ms DAWKINS - Could you give us an idea of what that would look like? From somebody being in their home to a protected bed - can you give us a bit of an idea what the steps could be?

Ms LIPSCOMBE - Nearly every government-sponsored health service on the north-west coast has allocated rooms with more space and extra services and extra equipment for palliative patients, yet they can't keep the beds free for when the palliative patients turn up. The nursing staff are constantly shifting people and upsetting all areas of health to put people in the best spots but it's really hard.

Ms DAWKINS - That is great information, thank you.

Ms OGILVIE - You said something then that really resonated with me about the fear of going into a shared ward which really strikes at the heart of the matter because I am suddenly going to a strange environment with people I don't know and I am dying and I don't want to do that publicly. Do you have some experiences that you could share with us around people who have expressed that concern?

Ms LIPSCOMBE - I'd like to say first that our nursing staff do everything they can to move the people they can and a lot of the time we'll get there by juggling people, which upsets a whole lot of other things for those people. Just the other night I had three elderly ladies in a room and it just so happened that the one man sharing the room with them was intellectually handicapped. They were all ladies probably in the first two years of their palliative journey but they still - the curtains weren't drawn properly and it upset the intellectually disabled man and all three women and there was nowhere to move anybody. I didn't want to upset anyone - and then the families start giving you a ring.

Ms BERRY - It is not just for the patient or client really, it's the family being distressed. They haven't got that private conversation space.

Ms OGILVIE - Are there family conference rooms, or is there a space?

Ms LIPSCOMBE - There is no dedicated space, as in acute care facilities, for palliative care, really. We make the most of the gaps we have.

Ms OGILVIE - So there is not even a room, where you can go in and say, 'Look, you are not going to survive this.'

Ms LIPSCOMBE - It's more like**, '**Let me just check if anyone is using that room first, and then we might go into there.'

Ms OGILVIE - That was my experience too.

Ms LIPSCOMBE - It's a protective journey, so we can bring them in, from the community, tweak them a little bit, hopefully aim to let them back out to their preferred place. That is not always possible either, when you think how sparsely people live, and where the services are.

Mr JAENSCH - That particular challenge of the way we live on the north-west coast, is a really hard one to service, is it not? Because it spreads our numbers out so much. With the protective-bed model that you were talking about within existing facilities, I expect that we are talking about Smithton and Queenstown.

Ms LIPSCOMBE - We need to start somewhere. We have two big hospitals up there, and we have lots of little ones. I do not know. We just need to start somewhere. We need the community to tell us if it is on the right way to a model they are after. I don't know if Queenstown would want to come to Burnie, to go to the hospice.

Ms BERRY - Most people from the west coast want to stay on the west coast.

CHAIR - They do, they want to stay in their community.

Mr JAENSCH - People from King Island want to say on King Island.

Ms BERRY - Stay.

LIPSCOMBE - It is so hard at the moment to manage them. We think we have 24-hour-a-day-palliative care, but we have 24-hour day care available. We can do things through the hospice and home-funding model, on a 24-hour-a-day pattern, but it is not palliative-care specific. I do not necessarily hear that in a lot of the arguments. I keep hearing the gaps are filled.

When I look at who is providing the service, Hospice Care Association have trained palliative-care volunteers. Specialist Palliative Care have trained nurses. Community Health have nurses who have done specialty emersion in palliative care but the other carer service providers are generalist carers. We are pushing them into a specialty, and we are not giving them an extra layer of education either.

Ms BERRY - Or support, probably.

Mr JAENSCH - With the rooms that are suitable and notionally available - if they are available - the sense I get is that sometimes when you need to be able to put someone in them, they have been requisitioned for another patient of a different type.

Ms LIPSCOMBE - Who may not be able to be moved?

Mr JAENSCH - That is right. So, the beds that are allocated for palliative care are not full all the time. If they are being reallocated, then there is a bit of turnover. Do you have any idea of what the occupancy is of the stock that we have.

Ms LIPSCOMBE - No, but I do note that the medical ward that I work on has 31 beds. I think we run at 29- to 30-bed occupancy. Single rooms are always the rooms that are filled first, on a needs basis. The three we had decorated for palliative style, which were situated away from the hustle and bustle, have to be used for general infection control, if there are no other rooms to choose from. Infection control is a priority.

Mr JAENSCH - It is a numbers game, isn't it?

Ms LIPSCOMBE - It is a numbers game.

Mr JAENSCH - With any of those centres along the coast, the numbers are so small, you can not have a two per cent float, or thereabouts, can you?

Ms LIPSCOMBE - No. Fifteen years ago we did have a float of beds, we don't have that anymore.

Mr JAENSCH - When you are talking about these beds, they are actual physical rooms that we are talking about here, as opposed to the way we talk about beds generally.

Ms LIPSCOMBE - These are over-sized single rooms with capacity to house families. We have even put in small kitchen and lounge facilities to make it more of a home-like situation so when we have to travel the palliative journey, we can make it as homely as possible.

Mr JAENSCH - Is there any sense then in the public conversation about this to distinguish the rooms from beds? A lot of argy-bargy goes on about beds and funding of beds but you are actually talking about some spaces that have been specially created. In our ideal world they would be available on call all the time, ready for the next person who needs palliative care. Others talk about creating a special facility full of those beds in another place; that is another model. On the north-west coast, though, we have this distributed system where one of those centrally would not help too many people.

Ms LIPSCOMBE - Our hospice volunteers would love to come into the hospital or any place that had protective beds and we would do our volunteer role. They could be in nursing homes, they could anywhere but we need to start with something.

Mr JAENSCH - Okay, it could be nursing homes.

Ms LIPSCOMBE - Our president is currently running a trial program at one of the nursing homes with our volunteers. Yes, there is a lot of capacity in nursing homes.

Mr JAENSCH - Is there a way of identifying that trial so that we could follow up on that?

Ms LIPSCOMBE - We do not have any protective beds there but we do have a volunteer program at Yaraandoo, which is our pilot program.

Ms OGILVIE - Do you want to talk about that?

Ms BERRY - Yes, we started last year. Pauline is the chaplain there who is also our president and a volunteer. She comes to training sessions to talk about spirituality to the new volunteers, so a very able person. Pauline actually does the referrals of clients - I still call them clients even though they are a resident - to myself. We are supported by the nursing home and I have three different volunteers who visit two clients a week. That might be quite short depending on the client on the day. It might only be 20 minutes or they might stay longer and do craft or watch a movie together.

It is around mainly clients that are bed-bound or room-bound and who cannot then access lifestyle and leisure programs that are already in the facility. Either that or people who have no family to visit. We also have on occasion provided an overnight sit in a facility so that the person will not die alone. I think a lot of people say there are people there all the time but if you are bed-bound you do not have someone with you all the time; it just cannot happen; physically it could not happen. We can provide that as well.

We are hoping that we can increase what we are doing now from Yaraandoo and we are going to start with another nursing home and start the conversation to see whether it would work there as well at Wynyard. That is the next plan, somewhere small. You have some places that already have quite a lot of volunteers. A lot of the lifestyle and leisure people have 30 to 40 volunteers, but generally out in the general community of the facility, doing craft or cooking or whatever.

CHAIR - In terms of the services you are providing, can you outline what your volunteers do?

Ms BERRY - Mostly our volunteers sign up to do what we call respite sits, generally in the day but we also do evening or night sits. We also provide transport to treatment. We transport people over here to see specialists or, in the past, to have radiation treatment in Launceston.

CHAIR - In the past?

Ms BERRY - Yes, in the past. We are still transporting but we are doing it to the north-west now. That is a free service; there is no charge for that so we do quite a bit of that. When our volunteers go into a client's home they are sitting with that client; they are not doing things for them, so there is no medication, no personal care. It is just being with that client for the time. It is generally between two and four hours at a time. It is giving the carer the opportunity to leave. It sometimes happens towards the end of life that the carer does not want to leave home. They can be within the home but the volunteer is still there so they can just call on them.

Ms LIPSCOMBE - We are a quality-of-life service. Unlike most of the other health care providers out there we are not providing health care; we are providing quality of life at end of life, so we empower the clients and their families. That is why it is so important to me that they have a safe journey to the next place.

CHAIR - I would like to go back to the earlier comment about the need for infrastructure around your clients. Could you expand on that? What do you really mean by that? You said it was well supported but you needed infrastructure around the clients. I was wondering what the word 'infrastructure' actually meant in this case.

Ms OGILVIE - Was it around equipment maybe?

CHAIR - Or is it connections, medical records, or what?

Ms LIPSCOMBE - We feel we can provide our service but we don't feel there is infrastructure in place for the clients' journeys. Where do they go to? They just go to the hospital when they need treatment and the hospital doesn't have a protected palliative pathway for them to travel. They are just lining up with the people with football injuries.

CHAIR - We have received evidence that there are key coordinators in the north-west.

Ms LIPSCOMBE - Okay, I get a phone call from the community to say they are sending a palliative patient in and can I send them straight to the ward, and we haven't got a bed on the ward so they have to go through admitting. They will go down there and get trapped in the casualty system and it will probably take a four-hour journey to make it the ward and they will have probably been on a very hard trolley for most of that time. They are dying and their journeys aren't protected.

CHAIR - I am trying to nail this down so we know what we're talking about because we aren't from your area of specialty.

Ms LIPSCOMBE -They have to wait for the public ambulance. They have to ring the ambulance number and wait two or four hours to be picked up and then they will be presented to casualty where they line up. They might get straight through but they have still going to have to go through a very slow process.

CHAIR - What would you want?

Ms LIPSCOMBE - It would be nice if there was a number they could ring that could come and pick up a palliative patient and they knew it was a palliative patient and got priority - come through, get directly link to a dedicated bed on the hospital that they already knew was free and then the doctors would come to the bedside.

Ms OGILVIE - And that they are received with the knowledge that they are dying, yes.

CHAIR - They aren't received with the knowledge that they are a palliative patient?

Ms LIPSCOMBE - Yes.

CHAIR - Right, but that doesn't make any difference to their journey?

Ms LIPSCOMBE - No, because the public health system is numbers based and on whoever arrives first gets the beds.

CHAIR - First in, first served.

Ms LIPSCOMBE - First processed, really.

Mr JAENSCH - It is a very difficult call, isn't it, because the other people might be a child with an injury or someone who has been waiting for their hip replacement for two years in pain, so they are all different heartstrings, aren't they, every single one?

Ms BERRY - Yes. There was a recent occasion on the north-west where a community health nurse rang an ambulance to take a client to hospital and it was a non-urgent ambulance that was sent and they refused to take the client because she had a syringe driver. There is quite a high percentage of our palliative care clients who are on syringe drivers and they refused to take her to the north west.

CHAIR - Was that a communication breakdown?

Ms BERRY - No, we can't work out why it happened. We don't know whether it is across the board or just the decision on that day but it ended up that they called an urgent ambulance and they took them, so I don't know what the issue was but that needs clarification because a lot of our clients have syringe drivers.

Mr JAENSCH - That sounds like a compliance issue whereby the non-urgent ambulance which is patient transport hasn't got it on their ticket to look after what might happen if something goes wrong to that person's special equipment.

Ms LIPSCOMBE - And it is urgent to the family; that's why they've called the hospital.

Ms BERRY - Yes, call an urgent ambulance, that's the first step.

Ms OGILVIE - The clock is ticking, that is the issue. Limited time.

Ms LIPSCOMBE - They may only be seeking analgesia as symptom management for a more managed end of life but it's the process to get to that place.

Mr JAENSCH - You have given us a breakdown of clients referred and admitted et cetera. Who generally does the referring, and are they predominantly older people with complications at their end of life anyway, or do you have a mix of younger and other people in there?

Ms BERRY - We get most of our referrals through the specialist palliative care service in the north-west. We also get self-referrals, some from practice nurses on the coast, different medical facilities and community health. Most of our clients are aged. Since I have been working with the service I haven't had any very young people. We haven't had any children, although I know there are children in the palliative care service. Our youngest client is probably about 30 and that is around transport. Generally the respite is aged because generally their carer is their spouse who is also aged.

Ms OGILVIE - Or deceased.

Ms BERRY - Or deceased.

CHAIR - Ladies, would you like to make a closing statement?

Ms LIPSCOMBE - Thank you very much; you had lovely questions. This is about people. This is about end of life and the people who are going to remember the journey are not the people who are dying; it's the people who stay, the people who talk about our service and promote it. I would really like it to be somehow or another not traumatic on families.

CHAIR - Thank you very much.

THE WITNESSES WITHDREW.

<u>Mr ALLAN CAMERON</u> WAS SWORN, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mrs Rylah) - Welcome. A committee hearing is a proceeding of Parliament. This means it is given the protection of parliamentary privilege. This is an important legal protection that allows individuals giving evidence to a parliamentary committee to speak with complete freedom without the fear of being sued or questioned in any court or place out of Parliament. It applies to ensure that Parliament receives the very best information when conducting its inquiries. It is important to be aware that this protection is not accorded to you if statements that may be defamatory are repeated or referred to you outside the confines of the parliamentary proceeding. This is a public hearing. Members of the public and journalists may be present and this means your evidence may be reported. It is important that should you wish all or part of your evidence to be heard in private, you must make this request and give an explanation prior to the beginning of that evidence.

Mr CAMERON - Just so everyone knows where I'm coming from, I came in today basically because I am interested in dying with dignity. I think palliative care is a wonderful thing and it is an ageing population we are dealing with - I am 83 - and more and more people are relying on palliative care and it all comes back to money because to have all the things we need requires money. I was very interested in Dr Ramsay's talk about some different things. The GPs in other countries may not understand palliative care.

As a humorous side to this, in Campbell Town we have great trouble getting doctors. Sometimes other nationalities come in. We had an Indian doctor who arrived and was going to be staying for months, but in the first week his wife said, 'I can't walk down the street and smell curry, I'm going', so they left. Country people, as Dr Ramsay was saying, have a lot of trouble getting GPs to come here in the first place and it is absolutely vital because more and more of my age group want to be treated at home. From what I have seen in the Campbell Town district, the GPs are magnificent, they work hours well above what they are paid for and we are very fortunate. They open at the weekends for an hour or so on Saturdays and Sundays and we are very fortunate. The palliative care people go around the various farms looking after elderly people who want to be treated in their homes and I hope we can keep up that sort of help.

As I say, it gets back to money. Where does the money come from to supply all these things? I think that very quickly sums up what I was talking about structurally.

Ms OGILVIE - I appreciate the difficulty of living in a small country town although it is not something that I have experienced, and it is really nice to hear that your GPs are available. Are you aware of any circumstances in which people have had trouble getting specialist palliative care services?

Mr CAMERON - Frankly, my answer would be no, because I have not delved at great length into what is happening. I belong to what they call a local district committee, which is part of a northern midlands group of people. I asked David Downie, the chairman of the Campbell Town Hospital, the other day how things were going. His comment was that Mr Ferguson was looking after Campbell Town and Oatlands very well and doing his best to overcome some problems, but I can't say anything specific about whether people are getting treatment or not. All I know is what I have seen.

Ms OGILVIE - I think we would be very interested to know what the local perception is. I realise that you did not come here today thinking you would give evidence.

Mr CAMERON - No.

Ms OGILVIE - I am sorry to ask you questions that you may not have researched. One of the great things about doing these inquiries is that we get to talk to people from all over the state who have very different perspectives on things. It would be helpful, even at a later date, if you wish to write some notes to us about the situation in Campbell Town and how the local community feels about their care. We had a chat during the break about dying with dignity and we had a lot of common territory around a dignified death and then there were some parts we were not in heated agreement on. Would you like, for the benefit of the committee, give us your view about those things?

Mr CAMERON - If Madam Chair will allow me, but it is outside the scope of your discussion.

CHAIR - It depends what you say. The focus of our discussion is around palliative care, so if you can cast it in that light we are very happy to take your comments.

Mr CAMERON - I have wide contact with people from various walks of life and I would say that 80 per cent of them want to be able to die with dignity when their time comes. They do not want to be treated in hospital, having their nappies changed et cetera. When their time comes, they want to go. Country people can use a rifle. I have seen someone who has used a rifle and it is something I would not wish anyone to see; it is absolutely horrific. That is why basically we want a choice and the question is why can't we have a choice? A huge amount of Tasmanians want a choice, but we are not allowed to.

During the last debate in Parliament a couple of years ago on the dying with dignity bill I went down and sat through all of that and then I read the *Hansard*. To be quite blunt, and you can quote me if you have to, what the politicians of one particular party said would make your hair stand on end. There was a lack of understanding and a lack of thought. Politicians are elected by us to look after our interests, not their own religious interests or their personal interests. Too blunt?

Ms DAWKINS - I endorse everything you just said about personal choice.

Ms OGILVIE - Is it your view that a dignified death is not available in the current palliative regime?

Mr CAMERON - It is a very tricky question. Dr Allan Bulman, whom I know very well from various associations, and I have talked about this subject. My local doctors in Oatlands said to me, 'Allan, I know your wishes and I will fix you up when your time comes'. The trouble is I do not go to Oatlands anymore. I am going to be coming up to Launceston, so I do not have that peace of mind. That did not answer your question completely, did it?

Ms OGILVIE - I was really trying to get to the heart of it: do you feel that under the current palliative care regime your choices to cease care and other options that currently exist are insufficient? The idea that a dignified death can only happen through euthanasia is probably a little limited. I am just trying to find your view on that.

Mr CAMERON - I don't think it would. When my time comes I want the peace of mind to know that I am not going to be held in hospital having my nappies changed et cetera. I want the choice when my time comes, the doctor will know - or I will know - that I want to be put out of my misery. Unfortunately we have Dr Nitschke who, in his own well-meaning way, created great havoc in this whole argument. I do not like the word 'euthanasia' being used, and through his own well-intentioned means he created a lot of unnecessary havoc. All we want is to be able to die - and our doctor knows our life is finished. My father-in-law reached a stage where he was in hospital, he wanted to die, he got pneumonia and they resurrected him. That is the only word I can use.

CHAIR - How long ago was that, Allan?

Mr CAMERON - That was about 20 years ago. My wife said, 'For goodness' sake, why didn't you let him die?'. The doctor said to her, 'Who the hell do you think you are, God?' She said, 'Yes, who do you think you are?'.

Ms DAWKINS - It has been interesting hearing over the last couple of days people talking about dying peacefully. There is so much around this peaceful death. We know not everybody dies peacefully. Death can be a really violent act. You have brought to the conversation that it is our own personal choice to make that decision, so we do not die and leave this world painfully. I endorse everything you have said.

Mr CAMERON - A great friend of mine, his wife was in hospital with cancer. A month ago he said to me, 'Allan, she wants to die. She is in terrific pain, they can't stop it, and she wants to die and no-one will listen to her.' What do you do? I don't want it to be like that.

CHAIR - Allan, these are personal questions and if you do not feel like answering them, I understand. Have you completed an advance care directive?

Mr CAMERON - Yes.

CHAIR - Do you have an enduring guardianship?

Mr CAMERON - Yes.

CHAIR - You still feel, even though you have both of documents, that your wishes may not be respected?

Mr CAMERON - Yes, frankly I do. It may be that under law, it is meant to happen but I do not know that it necessarily will. For instance, if I have an accident on the main highway, it is in my wallet that I do not want to be resuscitated. That's putting a huge responsibility on the ambulance officers, isn't it? But that's my wish.

Ms OGILVIE -Your wish should be respected.

CHAIR - The issue of the first responders has been raised in the committee regarding resuscitation because they have a first-response requirement. That will be part of the things we deliberate on. What would you want and what would make you feel safe and comfortable that your wishes would be met? What is it, that's missing?

Mr CAMERON - You are getting to the stage of a lawyer now. I don't know. All I want is to know that when I go to hospital - I've had a triple bypass and two of those are not working now, they cannot resuscitate et cetera, I am not sure what I am living on. I want to know that when I go to hospital, if I say to somebody - if I am still capable of saying it - or my wife, son or daughters can say, 'He does not want to be kept alive,' I want that -

Ms DAWKINS - That they will respect that?

CHAIR - Do you believe your family would endorse that?

Mr CAMERON - They do. We have talked about it. Eighty per cent of the population want it, quite frankly.

CHAIR - Very good.

Ms DAWKINS - Thank you, you are very brave.

Mr CAMERON - No, it is what 80 per cent of the population want, but we are not allowed to have a sensible discussion.

CHAIR - Thank you very much, Allan.

Mr CAMERON - Thank you for letting me talk.

THE WITNESS WITHDREW.