THE HOUSE OF ASSEMBLY STANDING COMMITTEE ON COMMUNITY DEVELOPMENT MET IN COMMITTEE ROOM 1, PARLIAMENT HOUSE, HOBART ON MONDAY, 8 AUGUST 2016.

INQUIRY INTO PALLIATIVE CARE

Ms FIONA ONSLOW AND **Ms KIM McGOWAN**, HOBART DISTRICT NURSING SERVICE, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR (Mrs Rylah) - Good morning, Fiona and Kim. Welcome to the hearing into palliative care. A committee hearing is a proceeding in 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 fear of being sued or questioned in any court or place outside of parliament. It applies to ensure parliament receives the very best information when conducting its inquiries. It is important to be aware this protection is not accorded to you if statements that may be defamatory are repeated or referred to by you outside the confines of parliamentary proceedings. This is a public hearing and 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 McGOWAN - The reason we requested to appear before the committee was to speak about our current project that concerns palliative care and also to give a bit of background on what it is that Hobart District Nursing does. We have been providing palliative care to Tasmanians since 1896. Through our records we can tell that probably our first palliative care patients were Boer War veterans, so we have been doing it for a very long time.

If I skip 116 years, around about 2012 it became very evident to us that the way in which we deliver palliative care wasn't working. In fact there were some major impediments to keeping people at home. Some of those impediments were that you couldn't provide care overnight, that people were forced into acute care because they couldn't access medications and nursing staff and, more importantly, support staff. Therefore people had no choice other than to go into hospital when end of life became unmanageable.

In 2012, after about 10 years of rolling out a model of care I have been working on, we finally got some funding. The last three-and-a-half years we have been piloting the Hospice at Home project. We felt this was exactly the sort of thing you should hear about. We have no guarantees of ongoing funding for Hospice at Home. It effectively ends in June next year, but we are acutely aware that the Australian Government and the Tasmanian government both recognise the value of the project. The Australian Government has certainly made all of the right overtures about it being the model of care for Australia. In fact Fiona and I have been invited to speak in Montreal in October.

It has been described as an Australian palliative care project with global implications. This is something for all Tasmanians to be really proud of - that we have developed this world-standard model of care. Now we all have to agree that this is exactly what it is, and that Australians have the right to be cared for in this way with the best quality palliative care delivered in home in community. In fact we have modified our language since the beginning of the project. Whereas we always said 'in home' we are now saying 'in community' because for some people the best and preferred place to die is not in the bricks and mortar of their own home. It may well be their community hospital or in another place of their choosing. If half the people in your community hospital are related to you or you worked with or grew up with, that may well be the most friendly comfortable place for you to die, rather than to die in a home that is perhaps five kilometres outside of town or you do not have family within your own home.

The Hospice at Home project has produced some amazing outcomes. Some of them obviously economics, some social, but I think for both of us the most moving outcomes have been for families. Although it is fairly obvious to you and everyone else, people have a better death within their home with good medication management. The most positive area has been how bereavement for families has changed and how the project has contributed to people not needing anti-depressants, not having multiple visits to doctors after the loss of a family member, being able to go back to work in a reasonable time, not having those years of grieving in a bad way that affects all society. Grief and loss has an affect on all of us.

We are very conscious we have limited time with you so we have chosen our subjects fairly carefully. Much of what we do is out in the public arena now. One of things we want to talk to you about today is medication management and how important an aspect of our project that is.

Ms ONSLOW - We have, over the last two years, been developing, through consultation, an emergency medication kit which is being implemented now. We have been working with our GPs with regards to the first people who are eligible for this. This is about looking at the Australian and New Zealand palliative medicine recommendation of medications for end of life and GPs being able to prescribe those to go into a kit, so if they do have symptoms at home, those medications are easily accessible.

The family will be educated through the caring safely at home program, a program that was developed in Queensland about five years ago. It is about how to educate people through a colour-coded system to use medication. So it is a consistent language for families to understand how to give the medication themselves if necessary. Also, if another health professional is within the home they have access to the medication, which currently is very difficult at times for people.

There are two levels of palliative care that seem to happen because we do have a specialist palliative care team. Palliative care, as Palliative Care Australia says, is everyone's business. Specialist palliative care plays a very important role in caring for the complicated palliative issues. They remain playing a very important role for the complicated palliative care issues in our community. There are also a number of general practitioners out there trying to manage the day-to-day symptoms for your palliative care that does not necessarily need input from a specialist palliative care team. This is where we are aiming to try and support those general practitioners with these medications and with these kits. It is those general practitioners who will be facilitating the use of these kits in the future. We see a lot of people who want to stay in their communities being managed by their GPs. When GPs have problems getting their clients' medication, we believe these kits will play a really important role over the next 12 months keeping people in their rural facilities. We have done a needs assessment and consulted the community. We are pleased to be at the stage of implementing these kits and going to be able to achieve tangible results in the community.

Ms McGOWAN - It is all very well to have the personnel coming in and out of the house, whether that might be nurses or GPs or paramedics, but if the drugs are not physically inside the house then the only result is to end up taking someone to hospital for an increased dose of pain relief or for something to relieve the nausea.

How the kits came about was, over the years of building this model of care, when we came to write the tender for this, I said to Fiona, 'I want this box in the house and I want it to look like what the Flying Doctors use.' At a time of crisis, our nursing staff, who all have iPads, can be face to face with the family and talk someone through how to administer medication. We teach our families how to do this at the beginning of their journey. That burden is taken from the family of having to make the choice, 'Do I ring an ambulance, do I ring a doctor, mum is crying, or in pain, or making horrible noises.' This is an integral part of the achievement we have made with Hospice at Home.

Ms ONSLOW - As much as we talk about bringing to the fore the conversation about death, everybody having advanced care directives and medical goals of care, we have to discuss how the workforce initiates this and puts it into place. If they are not feeling supported or do not understand how to deliver within a palliative approach, it is not possible to care for people at home. That is one of the things our project has made a big impact on.

We have over 60 contracts with organisations delivering palliative care in the home, and we have an expectation that it should be delivered within a palliative approach. From the people who are mowing their lawns right through to the THS, we have an expectation they are educating themselves about the palliative approach.

We are saying to people that this is something you have to think about, that is important when you are going to someone's home and delivering that care. That has been a gold standard of the approach we are developing because it is creating a whole-system change, not just an organisational-wide change. It has been the key of our model and why we know our model has global implications in how it can be delivered in the future.

Ms McGOWAN - One of the tenets of Hospice at Home is that wherever possible, the same health care team or community care team that was delivering their other care is being used to deliver their palliative care. It is embedded in primary health where are putting those resources into a community. The Hospice at Home model of care has increased employment in small communities. We have patients right across the state. Little towns dotted around that might have a single GP practice or a very small community health centre have expanded because of Hospice at Home. They have been able to not only employ new people but they have been able to maximise the hours of the people they already have within their community. It is a better use of resources.

These patients are being cared for by people they know. It is not a case of Hobart District Nursing Service riding in on, probably not a white horse more like a bicycle, and taking over. This is about community care for their own people. Given that we have now cared for 2 000 Tasmanians in this project, and countless family members because this is about family as well, even if we said five family and friends were also involved in this care, there are another 10 000 Tasmanians who are in a better place after the loss of a loved one than there would have otherwise been.

Ms DAWKINS - When you are talking about the pain medications kept at home, what would be the capital quantity of those medications and how would they be taken care of in the home for safety?

Ms ONSLOW - The Australian and New Zealand palliative medicines have some recommended medications. Within them are a couple of the S8 drugs of which we say they can only use one. Certain ones have interactions with other drugs they may be on, so we are making sure the GP is making the right choice as to what that drug should be. There are only about four other drugs and we are saying there is only a quantity of 10 ampoules each of those. Obviously we have had a lot of conversations with drug and alcohol and the pharmacy as to how to do that. They plastic wrap the drugs that go into the kit as another measure of safety. They are clearly labelled so you see the drugs currently go into the home. It is a much better process and we are getting a lot of support from the pharmacy organisations which are currently dispensing these drugs in having this done in a more streamlined manner.

Ms McGOWAN - If you opened the fridge door of most of the palliative care patients previously you would find ampoules of morphine rolling around in the egg section. This has made a great contribution to safety and security. The drug and alcohol teams that we liaise with were thrilled that this was going to be controlled, but they also reassured us about the amount of drugs that were going into the home and reassuring us that no-one was going to be interested in this small amount. There are really only the S8s, the narcotics, that would be of any interest. That is a natural thing for people to be worrying about. The public does not realise is that these drugs are already in these homes in much greater numbers and completely uncontrolled.

CHAIR - Does that mean that the drugs are audited each time your staff, let us say that the hospital's home care is over a longer period of time than a few days, do you audit and check and are you following it?

Ms ONSLOW - Our aim is every time the emergency kit is accessed all the participants of care - the GP, the specialist team which is involved, ourselves and other community nurses - are informed and then we review what their regime is for care. Do their regular medications need to change because they are needing these breakthroughs? Do we have to review this client's progress so they are not having to access these medications? Ultimately we are hoping that these medication kits go in and in three, four, five years time the GPs have actually got a better understanding of how to manage and they actually become redundant. It would be a lovely thing to see.

It is telling the GP, every time, things have changed. You need to do this now. You need to change that care for them and their regular medication management probably needs reviewing because they are accessing drugs out of that kit. Whenever that kit is accessed we are informed and obviously we do have checking mechanisms when people are going into the home as well.

Ms OGILVIE - I have a question that is allied to this kit, which I think sounds like a vast improvement from what I understand can happen. I recall having a conservation with [?10:19:18] Bill Dunn around titrations and quantities, and it is my understanding that somewhere exists a guide. Is that the basis of what would be allowed and how much would be allowed into the home and the kits at any one time?

Ms ONSLOW - What you are talking about is a palliative care formulary.

Ms OGILVIE - Yes.

Ms ONSLOW - That still exists and GPs can access that and that actually gives them some guidance about the interactions of drugs, what is the best levels of drugs to give and that really helps them with what I was talking about, those standard treatment processes.

Ms OGILVIE - It is protocol level stuff.

Ms ONSLOW - That still sits there and our recommendation is that the GPs putting together any medications for their general care should be there. The Australian and New Zealand Palliative Society had a look at the most common drugs needed for symptom management that are often not available to people and put out a list of them. These are things that are usually for nausea, vomiting, pain and agitation, which are some common side-effects that we see now. Currently people end up going into hospital because they can't be managed. They then have to go through a symptom management process and sometimes they never get back home. If we had an ability to put something in place and change the care plan while they are still at home rather than transporting them in and out of a facility where they don't necessarily need to be, those outcomes could be very different.

Ms DAWKINS - I have a question around patients coming to you from palliative care wards and hospitals. Is it something that happens very often that a patient is there, they've become a little bit better and are no longer comfortable in that setting so they can then go home and stay at home?

Ms ONSLOW - Yes.

Ms DAWKINS - Can they then go back again if that is required as well?

Ms ONSLOW - Absolutely. It's all about choice. We've even had people coming out of residential facilities and becoming palliative where the family have come to us and said they really don't want to be here they want to get them home and we've supported those families to get people home out of those facilities.

Mr JAENSCH - Thank you for your evidence and your presentation. I am interested in two areas in particular that I see reference to in your submission. First, advance care directives and how accessible and variable they might be from place to place in this jurisdiction; and second, perhaps in relation particularly to your medication management, if shared electronic health records is an area that we need to be putting a light on.

Ms ONSLOW - We have seen an increase in advance care directives during the program. Obviously we have the conversations with our clients as part of our admission process to encourage people to have advance care directives. Alongside us Palliative Care Tasmania have been doing a lot of work within their Better Access to Palliative Care funding. Something I have highlighted in my submission with my case study is that quite often patients aren't given those end-of-life conversations with their doctors very succinctly, which I think makes it difficult in having those conversations about ensuring that these advance care directives are put in place in a timely manner. We are certainly seeing improvements and I think the consistency in what we are using for advanced care directives is great. Everybody is using the same template and the same modalities of doing it. I think who has the conversations has improved a lot and the education that Palliative Care Tasmania has done has helped that. That has standardised how to have the conversation and all of our staff are trained to have those conversations, although we are fortunate to have social workers who can be at the forefront of having those conversations as well.

Mr JAENSCH - I understand Tasmania is the only state where there is no legislation surrounding advance care directives and how they are applied. Is there a different practice interstate that we should be looking at?

Ms ONSLOW - There is different legislation in every state. I am not sure and it is probably not my skill set to say which state does it best. I wouldn't know how to respond to that but I certainly know it is different. There has been no real testing in law as to what it means if you don't follow someone's advanced care directive, and because things haven't been well tested I think GPs sometimes wonder what sort of document this is as well. I have certainly had that feedback and I am sure other people will give that feedback at some time.

Ms OGILVIE - Just to chip in, that is my understanding as well, if that assists. That is not to say that things aren't already being done. It is about the clarity.

Ms ONSLOW - We certainly encourage them. I mentioned in my submission that we are looking at whether we have an opt-out option. Our expectation is that everyone will have an advance care directive as they come onto a program like ours, because it is an understanding we have with them that we would not be surprised if they died within the next 12 months, so these are the forms that they really need to be putting in place and they need to opt out if they choose not to do that and sign that they are opting out, so we know that conversation has been had and that people are encouraged to have them in place. We think they provide a good standard of how we are delivering our care for these people.

Ms McGOWAN - A common health record. Most of what we do with Hospice at Home is about case management and care coordination because we have all these other organisations that are contracted to deliver the hands-on care. Any one of our patients could have four, five or six organisations involved in their care, including separate parts of our own THS, and there could be parts of that that have different unit record numbers and case numbers. I have done some work looking at the Canadian model and the Northern Territory, where they have a common health record number. There are a number of things in the system that would change, such as who is prescribing medication; where is medication coming from; who is involved in this person's care; and would there be a quicker, more effective route to access care if someone such as our care coordinators could see their whole record in front of them. There are even the possibilities of research. When you have this common health record and you can see back through childhood, the advantages of phenomenal.

The Northern Territory model is fabulous and, when you think they are half our population, Tasmania is in the next best position to achieve this. This is something very dear to my heart and we need to seriously look at it. You just mentioned driving to Ross on Saturday. God forbid something should happen to you in Ross and you end up in Launceston General, because they won't bring you back to Hobart. You end up in Launceston and you don't have a common health record, so I think it really is our big next step, especially technologically, in Tasmania.

CHAIR - What is the factor that stops that happening at the moment?

Ms McGOWAN - I was in the emergency department for 15 years before this job and I have been in this job for 16 years, so 31 years ago we were talking about a common health record. In the emergency department, during different building stages, we literally put medical records in a bucket and dropped them down the stairwell on a rope, and it's really not that much different now. You had information scattered everywhere within the hospital. Of course that is a lot better now, but it was being talked about at least 30 years ago - and we're still not there.

CHAIR - What stops a common health record being created by the Tasmanian Health Organisation?

Ms McGOWAN - I think it's probably something that could be done by our own health organisation but then it's getting the buy-in from everyone else - for example GPs and an organisation such as ours, although we'd be there. It is the will, first of all, and then having that common buy-in from every sector of our health system - private hospitals et cetera - to achieve it.

Mr JAENSCH - And the interoperability of secure systems that have been developed to hold people's information privately.

Ms McGOWAN - We have a lot of work to do on our IT. We are fortunate to have just received word we will be doing a successful tender for the north and north-west of the state in clearing some waiting lists for Home and Community Care. One of the impediments to that is we have no common record management. At Hobart District Nursing we can do encrypted emails; we have faxes, and that doesn't happen within the rest of the state, within the government sector. In this project, we are going to be faxing people's information because we cannot be encrypted on email. We have a lot of work to do and it is a big investment and I appreciate that. I know how much we have spent at Hobart District Nursing over the last 10 years in this. It is a big investment but in the long term it is going to save an awful lot of pain and heartache. We miss things because of that. Our care coordinators are there trying to coordinate the best possible package of care for someone and then a month later we discover there is this service provider going in that nobody knew about. That is duplication and a waste of resources. Sooner or later we have to do this.

The Northern Territory has done it beautifully. We have had a few trips up there. We have a good relationship with the Northern Territory because they are very interested in Hospice at Home. We are helping them put together some submission that can a pilot site to deliver hospice at home to their population.

Mr JAENSCH - They have some complex issues regarding informed consent, haven't they?

Ms McGOWAN - Yes.

Ms DAWKINS - On medical cannabis, it is moving quickly in Queensland, New South Wales and Victoria. We hope it will move here too. Do you think there is a role there, in a suite of medications available for medicinal cannabis?

Ms ONSLOW - From a symptom management point of view, no. When you are talking about general management, there definitely may be. To be able to have GPs prescribe medical cannabis - looking at the best practice research of what they work with - I think that is reasonable. What we are talking about in emergency medication, it does not have a role within the kits we are talking about.

Ms DAWKINS - Not strong enough.

Ms DAWKINS - Those medication to are to top up what they already receive.

Ms OGILVIE - My question is around efficacy of pain management. Firstly, congratulations on what I think is a world-leading program. It is fantastic. What I am hearing about the kits going to the home seem like a complete step up from what is happening at the moment.

In my travels and talking to people around the tracks, the thing that strikes a chord with me are people who are very worried that at the end of life they will have excruciating pain. It weighs heavily on many people's minds, particularly those who have a diagnosis are moving - I was speaking to one the other day who are kidney failure - into that area.

Can you sketch for us your experiences with pain management? Are we seeing an improvement in the pharmalogical management or are their still gaps? Is there a resourcing issue? What could we do to alleviate that concern, if it is accurate?

Ms ONSLOW - Pain management, as a whole, is managed quite well. Where we have some problems, which is why we have the emergency medication, is the timeliness.

Before I came here I was looking at the calls we had over the weekend. Most of them were pain management. I was thinking if we had the kit in each of those people's homes we could have been much more responsive in how we treated them. Some to a point where an ambulance turned up and one gentleman refused to get in it, so we had to get somebody in to help them out. We did and they did mange to stay at home, and we did get the pain under control.

It becomes an issue. I do not think it is a point where people are out there days and days in pain. It does mean they end up not being at home and going into hospital, into facilities and it is what we got when we did our needs assessment. Specialists can probably talk more widely on this. Our general sense with the people on the packages is, yes, we do still see some symptom management issues but we see they become addressed appropriately, though not usually in their setting of choice.

Ms OGILVIE - You are addressing one of the big gaps with the kits?

CHAIR - Thank you very much.

THE WITNESSES WITHDREW.

Dr HELEN LORD, ANGLICAN CHURCH OF TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Good morning and thank you very much for an excellent submission and coming to give evidence today. This proceeding is a committee of Parliament and therefore parliamentary privilege applies while you are at the table. This protection is not accorded to you if statements that may be defamatory are repeated or referred to by you outside the confines of this room. This is a public hearing and your evidence may be reported. If you wish all or part of your evidence to be heard in private you must make us aware of that and give an explanation prior to the evidence.

Dr LORD - I was approached to provide the submission by the Bishop of Tasmania, Reverend Richard Condie, so I am speaking on behalf of the Anglican Church of Tasmania.

I have worked in palliative care in Tasmania since 1988. When the Whittle Ward was first established I was their first VMO, so I have worked in palliative care for a long time. I have also worked as a general practitioner so I work in both places. I have a fellowship in palliative medicine so I am a palliative care specialist when I work with the palliative care service.

I am currently employed as their locum. In the last two years I have worked in Launceston, I have worked at the Royal, I have worked on Whittle and I have worked with the community team. I am a member of the statewide reference group for end-of-life care which is looking at advance care directives and those sort of types of things. I mark for the College of Physicians for palliative medicine and I also teach medical students. I am doing quite a bit of teaching at the moment. I teach at years 4-5 goals of care, practical palliative care and I teach with the general practitioner training - GPT - and do a section with them on practical palliative care. That is where I come from. I am a member of ANZSPM, the society that has done a lot of the work around the medications.

The two things the bishop really wanted me to address were about making sure we had really good palliative care services in Tasmania. I think you have seen already this morning some examples of some really good services developing. We want to support the work of those services, and there are a number of services that work with hospital teams in palliative medicine. A lot of palliative care around the state is done by medical practitioners, GPs. A lot is done by other specialists within the hospital. It is everybody's business. I only get to see the difficult stuff when I am working as a specialist but in general practice I see the everyday, so in a way I cross both things. The other thing is to make sure any sort of legislation, particularly around advanced care planning and emergency provisions, protects the vulnerable in society. There are issues now.

I'd like to reiterate something that has already been said this morning. Those conversations about end-of-life care are really important. It is also important who has them. I am aware that people can easily become frightened and think they may be denied care if they put the wrong thing down, so it is very important who has those conversations with people. It is also very important that they have good communication skills and are able to really find out what people want and need and are able to address those things, and that people have a good understanding of capacity. The difficult ones are the ones I see when there are mental health issues, disability, homelessness, people being very frightened, people who are socially disadvantaged, people who are alone on their own. They often feel they cannot name a person responsible so that is a bit of a limitation.

In terms of the legislation as it exists, it is true our advanced care directives are not legally binding. What is legally binding is enduring guardianship. That process can be onerous for some people but it is the only way if people want to have absolute certaincy about their wishes being respected. However, even then, it is vested in a person, not in a form as such. Certainly people have to do an advance care directive then find the person responsible, and that has to be signed and lodged with the Guardianship Board. The other thing is that sometimes access to the Guardianship Board to find out about that information is difficult. The information side of things is very difficult. Usually these things always happen on a weekend.

Ms OGILVIE - 3 a.m. on weekend.

Dr LORD - Yes, when access is difficult. I have been in positions where you are left with having to make the best decision.

Ms OGILVIE - A judgment call.

Dr LORD - A judgment call, yes. That's a really difficult position to be in when people haven't got that. That is where the legislation is. The Guardianship Board does a really good job for people with disability, so that is an excellent -

Ms OGILVIE - It's their strength.

Dr LORD - That is their strength, so they are really good. I am not sure how the new Mental Health Act fits in with guardianship issues. That's something you might need to get some advice on. I have been trying to get my head around what that means - that's for people who have issues with capacity. The person responsible hierarchy framework is good.

CHAIR - In the guardianship?

Dr LORD - Yes, and provides also the capacity assessment. Capacity is something that is task-specific and can be regained. You need to have the understanding that capacity is task-specific.

The other issue I have with advance care directives is around community expectations. I have seen some very interesting advance care directives in my time. Some say, 'I want everything done', or 'in no way will I have CPR'. It is very hard because there are some instances where CPR is the most appropriate treatment, so it is about context and all those types of things. Communication is very important. As a medical practitioner it would be good to have some sort of advance care directives, and to have a bit of legal standing so we knew where we stood. People need to understand what can reasonably be expected. I quite like what is on the form that we are trying to get out, and at the bottom is something I think is very helpful. When you talk to people this is common in what they want. 'If there is no chance of recovery, or very little chance, I don't want to have life prolonged' - that is what most people want. That is good because it gets ticked.

Ms OGILVIE - So there are some triggers and facilitation for the thinking.

Dr LORD - Yes, there is some facilitation. The other thing I have seen is this form filled in by a relative, but it needs to be done by the person themselves. There also needs to be a check if that person has capacity at the time of writing.

CHAIR - Which person?

Dr LORD - The person concerned, the patient, writing it. There needs to be a check on that and somebody needs to have a look and see if it's reasonable. I suggest it needs to be endorsed by the person's medical practitioner. That would be the way to do that. The way general practice is funded at the moment, it would be nice to get a separate item number - but you would to speak to the Commonwealth about that.

CHAIR - I think we have received evidence there is a Medicare item number.

Mr JAENSCH - This goes to the format and legal status or statutory backing of what we have in the area of advance care directives. An advance care directive at the moment has no requirement for demonstration of competence, or informed consent, or a certain party or a fourth party check-off. I would imagine anybody would be very hesitant about complying with this at critical times. What protection is there? Absolutely nothing.

Dr LORD - The other thing known is that there is a change in preference over time. It tends to be that the older people get, and sometimes the more ill people get, the less intervention they want, however it is not always the case.

Mr JAENSCH - They might also be in a position where, if there is dementia, their new will cannot be expressed.

Dr LORD - Yes. It is very difficult and that is why I think there have to be caveats on it. Certainly when I am teaching medical students I say you have to look at this. You have to look and see where it is written and who it is written by. The other thing is it needs to be congruent with the values and beliefs. It has to be reasonable and it has to be congruent with those sorts of things.

In the medical context, in oncology there are new medications, the new targeted chemotherapy and things like that. They are making a bit difference to the way oncology is done. People who would have perhaps only had a life expectancy of a month or so are now living for longer than a year with reasonable quality of life. There are changes happening with those things. You may well get changes happening in other fields. That is why I think you need to have some sort of review mechanism of it. This is valid for this time. It might be 12 months.

The medical goals of care I have worked with, this is the form that is used in all the hospitals. That is really useful. However, I have personally heard of people who are going to hospital; they are a bit frail, they have gone in to have something restorative and they have been put down here. So we need education. They have come away feeling frightened about not being given proper treatment. It works both ways.

Ms DAWKINS - Is there a time when you think we have been leaving it too long as a community to have this kind of conversation, and if we have this in any stage of life?

Dr LORD - It is a bit like the conversations you have about organ donations and things like that. When this comes up it may be, 'Have you talked to your family about it?'. People who are disadvantaged, though, are those who are isolated and living on their own.

Mr JAENSCH - Estranged.

Dr LORD - Yes, or estranged. There are a number of people in our community who are like that and living on their own. They feel very much, especially when you have to put a person responsible down. So I think there needs to be some thought mechanism about their preferences. The thing I like about this is that people can put down their preferences. 'If I have to go into aged care, this is where I would like to be. I would like to be close to my community.' Often people want to name a place of care and have that respected. Sometimes it cannot be done. This is the place for it.

Ms OGILVIE - Thank you so much for coming in. I am aware of your deep knowledge and experience in this area. I have met somebody recently who is 92 and solo and had that conversation. At the other end of the spectrum, though, is an experience close to my heart - when you are making decisions about a child or a baby. At the moment, really your only legal mechanism around that is 'do not resuscitate'-type orders and conversations with staff. Is there a role for some sort of advanced care directive in that scenario or is that best left to clinical judgment?

Dr LORD - I think it has to be conversations with parents.

Ms OGILVIE - I have been through a very similar thing.

Dr LORD - And it is case by case. It is very variable.

Ms OGILVIE - It is more around the ageing bracket, the need?

Dr LORD - Yes. It is case by case and it has to be the parents who decide.

Ms OGILVIE - In your view, is the non-binding nature of the advanced care directive preferable because it leaves that clinical judgment open and context open, as thing change?

Dr LORD - I think there needs to be a conversation. If it has to be legally binding you have to have a lot of safeguards in there. We cannot always guarantee this is what is going to happen.

Ms OGILVIE - No. It feels a little bit like a birth plan to me. You express your great hopes and desires.

Dr LORD - Yes and perhaps it shouldn't, a directive -

Ms OGILVIE - Maybe it is not the right word.

Dr LORD - Directional, maybe. It provides direction, maybe.

Ms OGILVIE - Yes. That is a very good point, thank you.

CHAIR - I have question in regard to enduring guardianships. I have had some experience of seeing those with clients in a previous life. I note in your submission the issue you raise about the person who has been appointed as the guardian, often is of a similar age. It is similar to hiring a younger solicitor, so they outlive you. Can you reiterate what you think is important in regard to this? Should enduring guardianships have a time frame?

Dr LORD - They should have a time frame.

CHAIR - And be reviewed?

Dr LORD - Yes.

CHAIR - Somewhat like the superannuation requirements, you have to review them every five years or thereabouts.

Dr LORD - I have started to come across people who have an enduring guardian, and the enduring guardian is more demented than the person.

CHAIR - Yes.

Ms OGILVIE - I am aware of one of those right now.

Dr LORD - There needs to be a review process. At the moment it would go to the Guardianship Board. There has to be a process but there also has to be a review and the cost can be prohibitive to some people.

CHAIR - I assume it would be ideal if the person who has granted the enduring guardianship is again granted it at review, as long as they have capacity. We would not want it to go the Guardianship Board to determine they be an enduring guardian, if they have capacity?

Dr LORD - Yes.

Mr JAENSCH - You are eminently qualified to be providing us with a submission of this in your own right. I am interested the bishop came to you. I would too, if I was in his position. I am interested that your submission constitutes the Anglican Church's submission. What is your agency with them?

Dr LORD - I am an active member of a parish. I lead a small group. I do prayers. That is my faith.

Mr JAENSCH - The bishop was keen that because of the Anglican Church's engagement with palliative care?

Dr LORD - The Anglican Church provides chaplaincy and all those agencies. They are integrated. It is not just the Anglican Church who provides it. There are lots of agencies and when you are working, any spiritual adviser is welcome. It is not exclusive. That type of thing is not exclusive but amongst the Anglicans, people in general are very welcoming of having that pastoral support and ensuring it continues.

There is a lot of informal support that is done by Anglicans out in the community, making meals, visiting and minding the animals. When you get out at that community level, there is a lot of support. It is about whole of community, a caring community. They are very much values that are at the fore in the Anglican Church.

Mr JAENSCH - I am interested in your heading, the title of submission, we talked about providing a good death.

Mr JAENSCH - I am interested in your heading, the title of the submission we talked about providing a good death, which I think is a conversation we need to have more of in general in our community. As someone who has trained and practiced in medicine, could you comment on how well equipped our doctors and our medical system is to providing a good death?

Dr LORD - I would think they are getting better. Communication has become much better taught, much better appreciated in the last five or six years. I examine. They all have to undertake an observed, structured, clinical examination, which is an OSCE. They have to pass a number of those and I am doing exams for them next week. A lot of that is about their communication skills. Communication is core of this, plus having good symptom control. Communication is the core and being able to collaborate with a number of different people. No one person can do everything.

Mr JAENSCH - I have heard expressed from people representing colleges of surgeons and such that their game is all about life. What do we need to do to legitimise or to deal with that need for good death to be something that we administer?

Dr LORD - The College of Surgeons are starting to talk a little bit with the College of Physicians. There is they are starting to use some of the communication stuff that we use.

Ms DAWKINS - They see death as a failure, do you mean?

Dr LORD - Yes.

Dr LORD - I think it is perhaps a generational change.

Mr JAENSCH - Also, to learn to deal with a situation where people might realistically opt early on that they do not want to have cataract surgery, or to try to save a limb or something like that. It might make their end of life far more complicated than it needs to be, for something that they may not use.

Dr LORD - A lot of it is also empowering people to seek that second opinion. We actually see patients being better educated. It has to be a whole approach to health literacy and all those type of things are very important.

CHAIR - Why do you think that the GP, the everyday clinician, is not beginning the conversation early enough? What stops them beginning the conversation?

Dr LORD - Some people get quite frightened. I have a couple of patients I have not been able to have the conversation with. They are general practice patients and they get very defensive and they really worry. It is anxiety, I think. I think the conversation there probably needs to be that they keep coming back to me, so the way I am actually framing it more is I am here to look after you. I think that seems to be the way. That is the way it is going, there is fear.

It takes time. If you go into all the things that are needed to fill one of these in, I tend to do it over a number of consultations. It is difficult to get people back. It is difficult to engage with some people and again it comes down to the isolated. You have to be able to engage, you have to be able to communicate. You have to able to say this is important for you. In education too, we need some education and there has not been any education done on this for a while. There is a need for education that needs to be properly resourced and funded.

Ms OGILVIE - Education to whom?

Dr LORD - Education to GPs. The best way of getting that done would be to make it so some people get their CPD points.

Ms OGILVIE - Join the lawyers in on that as well.

Dr LORD - Yes, that is the best way of getting it done.

CHAIR - Thank you very much again for an excellent submission and for your time today.

THE WITNESS WITHDREW.

Ms ALISON LENNOX WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Good morning, Alison. 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 fear of being sued or questioned in a court or any place outside of parliament. It applies to ensure that parliament receives the very best information when conducting its inquiries. It is important to be aware this protection is not afforded to you if statements that may be defamatory may be repeated or referred by you outside the confines of the parliamentary proceeding. This is a public hearing, so members of the public and journalists may be present. This means your evidence may be reported. It is important that should you wish to have all or part of your evidence be heard in private you must make this request and given an explanation prior to giving the relevant evidence.

Ms LENNOX - I became involved because I had such positive experiences, so when I saw the little ad in the paper I thought you needed an ordinary person like me telling you that this system, as I experienced it, is great, but more people need to know. There needs to be more community discussion so that it becomes the norm rather than something horrific at the end of someone's life.

CHAIR - In reading your submission I now that your parents clearly had some time. At what point did they become engaged with creating their advance care directives?

Ms LENNOX - Probably when we could see mum in decline, so when she was about 86 or 87. She still understood things but she did have dementia, so we knew she was going to get to the stage where she would not be able to make a statement that could be witnessed and all that sort of stuff. We did that with mum before she went into a massive decline, and then I said to dad, 'Come on, let's do that too', and I have done one as well. It stimulated us all to do one so we're sort of ready.

CHAIR - Yes. Very good.

Ms LENNOX - It means that you talk to your family then, so all my children know what the deal is with me. There are six children with mum and dad, so we all talked about it, which was really good.

Mr JAENSCH - Alison, just for our knowledge and for the record, would you be able to take us through the steps? How did you find out about advance care directives? Where did you get paperwork or advice from? What was it actually like for you as a family doing it?

Ms LENNOX - It was a bit tricky at the start because we couldn't actually find an advance care directive, but this was probably seven or eight years ago. I asked mum's GP and she did a bit of research and then emailed me one, so it wasn't too hard to get. I honestly cannot remember where I first heard about them or where that happened, but mum has three sisters and they all have lived to a very old age, but a very unhappy old age, and we could see we didn't want mum to go through that. She's still got one alive who is 97 and really unhappy to be in this world, but has been kept alive.

Mr JAENSCH - In Tassie?

Ms LENNOX - Yes.

Mr JAENSCH - You were sent a form, a template, were you?

Ms LENNOX - Yes.

Mr JAENSCH - Did you just read it and work it out yourselves, or did you do that with your GP or with -

Ms LENNOX - No, we just did it, because even though it looks like a very complicated form, it is about six pages long, really all you've got to do is make sure you've got the name and it's witnessed. Mum and dad just said, 'We do not want to be kept alive at the end of life. No major resuscitation, no major operations when we're in old age, nothing that will keep us alive when really nature is taking its course.' So it was really simple, we took that to their doctors, they witnessed them, I think, they kept them on file and I always made sure everybody knew where they were so whoever ended up going to hospital with them took them with them.

Mr JAENSCH - Were you prompted to register them in any way more formally than that, or just have them with your GP and trust that?

Ms LENNOX - No, that seemed to be enough, and the fact that we had them at home, so there were strict instructions - 'If you call an ambulance for mum or dad you must take this form'.

Mr JAENSCH - And you mentioned you were there at the ED with mum?

Ms LENNOX - Yes, and it seemed they had a copy of it. I think the doctor must have sent it through.

Ms OGILVIE - That is very organised.

Mr JAENSCH - How did that actually work?

Ms LENNOX - I had taken it with me, but the head doctor called me in and said, 'Look, I know you've got this advance care directive for your mum,' so it had sort of got there, which is a bonus.

Ms OGILVIE - By osmosis.

Ms LENNOX - Yes, but it would not have mattered because I had it there. The only people not accepting of it very much are the ambulance people. It is really interesting, it's like, 'No, we're here to save your mother's life,' and it's really hard to say, 'No, look, it's okay - no treatment.'

Ms OGILVIE - Just stop.

Ms LENNOX - Yes, 'Just get mum to hospital' - that was interesting.

Ms OGILVIE - The district nurses have mentioned that as well. It's a cultural thing, isn't it?

Ms LENNOX - It is. That's what their job is, isn't it?

Ms OGILVIE - You appreciate where it is coming from.

Ms LENNOX - Yes, definitely.

Mr JAENSCH - I was interested in other members of the family being in on the process as well so that it was accepted and known. How did you bring others into it, or was it just your parents and your GP and yourself who did it?

Ms LENNOX - It was probably just the four of us initially, but I did let the others all know. In a way I was sort of the coordinator of their medical care. Another sister was coordinator of financial and business stuff. I just did the umbrella of their personal health care.

Mr JAENSCH - That's terrific. If that works, that is fantastic.

Ms LENNOX - We were really lucky. When there are six of us, you're going to find a couple who can do it without too much hassle, I hope. The only ones who perhaps might have intervened for religious reasons live in Canberra, so they just had to accept what was going on. Even though I say they were okay, I think they thought, 'Aren't we lucky someone's looking after mum and dad, so I'm not going to argue'.

Ms OGILVIE - I am so pleased you have come today because it is great to hear an experience of how it has worked well. It could be very positive if more people know about it. You said in your evidence you don't remember how you found out about them. Do you think there is a good reason to be having a bigger communication campaign? As you move around your friends in your age bracket, making these decisions, do you think they would be aware of advance care directives?

Ms LENNOX - No, they're not. I tell everyone I know and I have a blank copy of one. It makes it so much easier. I was talking to mum's brother today, who is only 82, but he has one in his drawer. I said, 'Robert, have you filled it out?', and he said, 'No, because it looks a bit long and complicated'. I told him to do the first bit and the last bit and sign it. He is determined not to linger; he doesn't want to get to 97 like his sister. I tell all my friends, especially ones who are looking after their parents. It was probably six or seven years ago that the GP didn't have a copy. She probably has now but maybe there could be a brochure in the waiting room. They have brochures for everything else.

Ms OGILVIE - And with lawyers and accountants as well. It doesn't have to be just in the medical space.

Ms LENNOX - We are getting better about talking about death. Usually it is all hush-hush but it is so much better now talking about palliative care. People get to know the Whittle Ward and St Johns, so it's getting better all the time and more public. Getting your hands on the form and then filling it out is the bit perhaps people need a nudge on.

CHAIR - Are you aware of Hospice at Home?

Ms LENNOX - Yes.

CHAIR - How would you have seen that integrated? I know it's a different time frame and your parents passed away earlier.

Ms LENNOX - We did have their help one night, two nights before dad went into hospital, and it was great, but getting on to those systems is very hard. There are all these wonderful services but it is very time consuming. With continence care for dad they said, 'We need to interview your father' - and that was a three-hour interview talking to dad about continence issues. I'd already told them the whole story over the phone but they still had to come and meet him and talk to him about it. That's the last thing he wanted to talk about. That was one massive interview and then the hospice in the home. Although we had all these other things helping us, every time you asked for that next step you knew you had to have another interview process, and dad hated it. He would do it and smile and chat to these people, but it was an invasion and it exhausted him. It was never just 20 minutes; it was this huge questionnaire.

Ms OGILVIE - Too much process.

Ms LENNOX - Yes. I had to answer nearly all the questions. It was giving him a chance but he didn't really understand. Every now and then he would say, 'What are all these people coming for?', and you would try to explain it because you didn't want to keep him out of the process, but I had to answer all those questions; he didn't know. It isn't easy to get these services but once they start - hospice was great; the girl who came was wonderful. We had 24 hours without any of us having to be there because this girl took over for a while.

CHAIR - Was it your experience that the repeated and lengthy questioning had a negative impact on your father?

Ms LENNOX - I would say at the time it did, but he very quickly forgot. It was like he kept forgetting he had cancer and was going to die. He just loved talking to people in the end and he talked to them about everything but what they were there for, which is probably why it took so long.

Mr JAENSCH - This is very interesting in hearing your experience of it because we are hearing from a lot of people who are providers of services or parts of service. You are someone who has been the process with your family members. If all the people who are coming were asking the same sorts of questions, then if there was part of the preparation of an advanced care directive that documented a lot of that case history in such a way that everyone who needed it could get most of the information that was there already, and then only ask the specific things that related to their service, that might make the whole process a little less cumbersome.

Ms LENNOX - I don't know putting it in the advanced care directives is the way to go.

Mr JAENSCH - Or as a background.

Ms LENNOX - Or just permission from the person and their family. The cognate group can go and talk to the nurse who is the regular visitor, so it all gets shared without the patient having to go through it.

Mum and dad were also cared for by OneCare, so they had people coming in to bath and all that. That was a nightmare situation. You could not get anything changed without a massive assessment and a massive interview. I said to them in the end that I would rather do it myself than go through the drama. You just want an extra shower a week. It was a massive process to get that organised. The OneCare red tape paperwork whatever caused more drama than anything else. If their paperwork could have been shared with everybody else and it was all done by email or phone, then bingo.

Mr JAENSCH - It sound like a job for red tape reduction.

Ms LENNOX - Definitely, I beg you, especially for those providers of in-home care. It is a nightmare.

Ms OGILVIE - We had some evidence this morning around process improvements with the sharing of information and what it might look like if the information was better coordinated. This sounds like another quite different example of that. Would it help if, in your father's situation, instead of you trying to be the one who coordinated the dissemination of information, it was actually the GP or the trusted nurse or someone else? Or do you have to be particularly involved because you have your finger on the pulse?

Ms LENNOX - You know the day-to-day nitty gritty little things and it can change so quickly.

Ms OGILVIE - Coordination point might not be that helpful?

Ms LENNOX - I would still have to tell that coordinator. Mum has deteriorated and she cannot do this anymore. We had so many people we had to report to that it still was better. There might be situations where there is not that core person.

Ms OGILVIE - We heard a bit of that this morning. Do you have any ideas, having had your personal experience, how it might be improved in practical terms? You mentioned the OneCare situation. We call it red tape but I think it is process improvement.

Ms LENNOX - Yes. I can't think of any more-polite words but they are covering themselves constantly.

Ms OGILVIE - Insurance.

Ms LENNOX - It is. Even the girls who came into clean. Everything has to be written down. There were some things they were not allowed to do, so it wasn't helping you because they could not do that thing you really needed them to do. So we would have to go and do it anyway.

Just proving to them constantly that you needed that, and then they seemed to have to come and witness it. You felt they were not trusting what you said. You felt that they felt good about their job because they were coming and spending time with you, but I would say, 'Please just spend time with mum and dad, because I need to -

Ms OGILVIE - I need to have my breakfast.

Ms LENNOX - Yes, something like that, rather than this constant filling out of forms and proving everything.

Ms DAWKINS - Were you were working during this time, because it is a full-time job?

Ms LENNOX - No, I had just retired, so it was very lucky that I had. I didn't retire to do that, but it just happened, and the need became great.

Ms OGILVIE - What was your profession before you retired?

Ms LENNOX - I was a teacher.

Ms OGILVIE - Right, no wonder you're practical. It comes through.

Ms LENNOX - I said to someone the other day who was really resenting what they were doing, 'Just don't, because you'll be so glad.' When they die you go, 'I've done everything I could and they went peacefully', and it's just a nice feeling.

Ms OGILVIE - It does become very positive.

Ms LENNOX - Yes, and you have no regrets, that's the best thing, even though you are still sad. That's the other thing about public education. We need to nurture more acceptance that people are going to die. In the workplace, in nursing homes, everybody needs to accept that we are all going to die at some stage. I think it is happening now, but it is just an interesting slow process. I understand with young children, babies or whatever, but so many people said to me, 'How are you going to get on without your mum and dad?' Well, I am quite accepting that it is a natural process and as long as you do what you can and they die as beautifully as they did, that's good, isn't it?

Ms OGILVIE - We all go in the end, don't we?

Ms LENNOX - Exactly. You just have to hope for a nice process.

Ms OGILVIE - And people who are around to care.

Ms LENNOX - Yes, and the scary thing is that a lot of people don't have anyone.

Ms OGILVIE - There are quite a few.

Ms LENNOX - That is where the officiousness can take over and make it not a pleasant thing. Then again, you get places like St Johns with Helen or the Royal with the lovely ones we had, and that's what they do and they do it so well.

Ms OGILVIE - I have one question left. You mentioned the workplace and the acceptance of the natural progress of life ending in death. We have heard some evidence this morning around bereavement and how a good death, in a sense - a natural and nice passage out the door - has positive impacts on bereavement. Do you think the positive experience you had assisted with that? Maybe you have some reflections on your cohort of friends who haven't.

Ms LENNOX - Definitely. I think even a couple of my sisters who live on the mainland still struggle. One of them said to me, 'Why are you coping, why aren't you a mess?', and I said, 'Well, I think I was lucky enough to go through the process with them.' They were physically away. They could have come down and joined in, but they chose not to. They came to their funerals. It always amuses me how people do that, but that is their choice. I definitely feel really lucky to have been there with them.

Ms OGILVIE - That was a positive process for you?

Ms LENNOX - Yes, massively. Apart from the fact that the practical Virgo in me just kind of makes me deal with stuff, I do think it made a huge difference.

Ms OGILVIE - That is interesting.

Ms LENNOX - The staff in both places gave you the space to do that. They were fabulous. They are just thoughtful, caring people. They didn't shut you out. In the olden days I am sure you wouldn't be allowed to be there, like dads didn't go and see their children born.

Ms OGILVIE - I was going to say childbirth again, the analogy.

Ms LENNOX - Whereas now it is just accepted that you have company when you're leaving this world, when you're dying.

Ms OGILVIE - We're allowed to say 'dying'.

Ms LENNOX - Exactly. So many people say, 'Your father and mother have passed?', and I say, 'Yes, they've both died.' I think it is really important it is not something to be scared of.

Ms OGILVIE - That word is not taboo. We use practical language in our house as well. That phrase 'passed' seems to be a bit of Americanisation that has come in. I was in Ireland recently having similar conversations. They are very practical people and I see some similarities with what you're talking about, having gone through the journey and it not necessarily being a negative experience.

Ms LENNOX - Yes, definitely.

CHAIR - We greatly appreciate your evidence, so thank you, Alison, for making time for us today.

THE WITNESS WITHDREW.

Mr TIM HYNES, MOTOR NEURONE DISEASE ASSOCIATION OF TASMANIA INC, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Welcome, Time. A committee hearing is a proceeding of parliament. This means it is given the protection of parliamentary privilege, an important legal protection that allows individuals giving evidence to a parliamentary committee to speak with complete freedom without fear of being sued or questioned in any court or place out of parliament. It applies to ensure the Parliament received the very best information when conducting its inquiries. It is important to be aware this protection is not afforded to you if statements that may be defamatory are repeated or referred 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.

Mr HYNES - I want to thank the committee for accepting our submission and inviting us along to contribute from the perspective of MND Tasmania. In my capacity here I am representing as president of Motor Neurone Disease Tasmania.

Ms DAWKINS - There is no cure, for motor neurone disease, is there?

Mr HYNES - No.

Ms DAWKINS - So how long is it between the diagnosis and the discussions around the directive?

Mr HYNES - Regarding the general trajectory around motor neurone disease I am going to talk averages. From the average point of diagnosis to death is between two and a half and four and a half years. From the moment you get a diagnosis from a neurologist to dying is somewhere in that range, typically. The process of diagnosis can take up to 18 months because it is a process of elimination, so you kind of hope for MS or Huntington's or other degenerative neurological conditions, because MND is like a death sentence. It is a process of elimination generally.

Advanced care planning is really important as early as the patient and the family is comfortable having that conversation because speech is affected with motor neurone disease. In almost every case speech will be affected. The muscles are also affected so writing and speech becomes a communication issue for the wishes of the patient and their family.

Mr JAENSCH - What is the normal progression of the disease? You have mentioned muscles and speech amongst other things, but is there a cognitive component as well?

Mr HYNES - Generally not, although the research tends to indicate that frontotemporal dementia is being linked to all of motor neurone disease patients, so up to 50 per cent could suffer some form of frontotemporal dementia.

Ms OGILVIE - Could you explain frontotemporal dementia?

Mr HYNES - Essentially some of the symptoms in my experience are kind of inappropriate laughter, and when I say inappropriate I mean out of context crying, laughing and other emotions.

There is also some loss of inhibition in some cases as well. Generally for a fair part of the journey of motor neurone disease, it is mainly physical deterioration. For a lot of patients that starts with the peripheries - fingers, hands, legs, arms - and then it comes inwards to speech, breathing and swallowing. For some people who have the most rapid progression it starts with their speech first, so they can be walking and writing and running up until the day they die because it has progressed the other way, which is speech and swallowing, which generally means a faster progression.

Ms OGILVIE - Is the cause of death usually inability to breathe?

Mr HYNES - Yes.

Ms OGILVIE - So the shutting down of organs?

Mr HYNES - Not necessarily the organs themselves. A lot of the muscles are voluntary muscles that will shut down, but eventually breathing becomes so compromised that they are susceptible to pneumonia. They cannot expel things - or choking in some cases as well.

Ms OGILVIE - Not the heart?

Mr HYNES - No, not the heart. I do not have a clinical background but that is a kind of autonomic nervous system so it just happens, like digestive systems.

CHAIR - So those parts keep working - digestion, the kidneys and the liver.

Mr HYNES - Largely. It is generally the breathing and the swallowing that are the biggest concerns at that very end-of-life stage.

Ms OGILVIE - Thank you very much for sketching that; it is obviously a dreadful disease. If you had the magic to change one thing we do around palliative care and end-of-life decision making for people with motor neurone disease, what would be the key in your mind to improving what we can do with services and conversations in the community? Do you have some views you would like to share on that?

Mr HYNES - Yes, I do. I suppose this is from reflections from our members and what we have been seeing around palliative care in Tasmania, which is that there still seems to be quite a lot of variability between the regions about what is available and what is delivered. When I say that, the biggest thing I think you will find is consistency around the palliative care services that people can access in parts of the state, and particularly the multidisciplinary nature of palliative care services. What I mean by that is being able to access nursing allied health, palliative care positions, palliative care volunteers et cetera so they can be well supported and they can get early referral to services. Those teams together in that multidisciplinary environment generally start the conversation around end-of-life planning and advanced-care planning with the GP and the families.

Ms OGILVIE - Yes.

Mr HYNES - The best case scenario is you would also have a neurologist as part of that conversation. Neurology is a huge issue in Tasmania. In Hobart, you might know about that but -

Ms OGILVIE - Yes.

Mr HYNES - In Hobart there is what we would say is an adequate number of neurologists. In the north and north-west it has been really troublesome since I have been involved, probably for the last eight or nine years - motor neuron disease, fly-in, fly-out services, neurology in Launceston. I do not think there is any north-west based neurologist, which would be probably hard to expect anyway. The north-west struggles, and a lot of our members go to Melbourne. They fly to Calvary in Melbourne and get service there.

Ms OGILVIE - Yes. How many members do you have?

Mr HYNES - We think we have almost about 95, 96 per cent of MND patients as part of our membership. The prevalence would be about 35 to 40 people with MND at any point during the year. Incidents newly diagnosed each year I think is about 10 to 15 per year at the moment.

Ms OGILVIE - Would that reflect other states and territories? It is not an MS-type preponderance in Tasmania?

Mr HYNES - No, we do not seem to have higher incidents because of the more southern aspect. We seem to be in line with the other states and territories.

CHAIR - It used to be a consideration, did there not, that there was a motor neurone issue?

Mr HYNES - With MS, I am not sure if that is still the case around the position to the equator. That is not the case for MND as far as we know.

CHAIR - You made the comment about the people in the north and the north-west having to fly to Melbourne. If people with Motor Neuron Disease deteriorate specifically through their lungs and their ability to breathe, however do they get service in Melbourne? How can they fly?

Mr HYNES - When I say 'Melbourne' I am talking specifically about neurology. The neurologist will not necessarily have a lot of direct service delivery with someone towards the end of life.

CHAIR - So is it in the diagnoses?

Mr HYNES - Yes.

Mr JAENSCH - There has been a neurologist from Melbourne coming down to the north-west, but not anymore. There is a little bit of a gap there.

Mr HYNES - Launceston is trying to service the north-west. Some patients are choosing obviously to travel to Launceston to get a timely diagnosis. What I was talking about there with Melbourne is essentially the neurology services and the whole diagnosis process, to try to speed it up.

CHAIR - That has helped me understand.

Mr JAENSCH - Tim, I have had occasion to be speaking with some families of Huntington's patients recently, and they have raised with me the issue of how Huntington's is manifesting in people in their 20s or 30s or 40s and progressing then through a number of stages to the point where families then are not well-equipped to provide all the care that they need. Often these are younger people, who are ending up in an aged care environment where there is support.

They have spoken to me about the need for a facility where people who are not dying from old age, but who have complex needs, can be supported, including swallowing and other types of assistances where they need proper 24-hour nursing care. MND patients and their families are in the same position.

Mr HYNES - Yes, definitely. We would call that young people in nursing homes or young people in residential aged care. By young people we mean my dad, for instance. He had MND and he was 60 going into a nursing home with residents aged 75 to 80-plus.

Ms OGILVIE - What is the age distribution?

Mr HYNES - Your typical onset of diagnosis for us is probably a lot older than, say, Huntington's and MS. Average age of diagnosis is probably 50 to 55 around the country. The big difference with MND is rapid decline. If you are diagnosed at 50 then you could quite easily need a nursing home by 52 or 53, which is still very young to be in, for lack of better words, an old persons' home.

Ms OGILVIE - Yes, it is a nursing home requirement rather than an aged care facility in that sense?

Mr HYNES - Yes, that is right. We have seen a need for a different model that can cater for people who are younger but going into residential facilities.

There are instances in Brisbane where there have been dedicated facilities, essentially crowd-funded, to have young people in nursing homes. Some of whom are MND patients as well. That makes a big difference.

CHAIR - Is Hospice at Home care appropriate for MND patients as they come towards the end of life, or is that not appropriate?

Mr HYNES - No, it is a good segue. The other thing I was going to say is a lot of people desire to be able to stay at home and die. There are not a lot of people, from our anecdotal evidence, who would choose to go into a residential facility even if it was age appropriate. The Hospice at Home and some of the programs that the Better Access to Palliative Care program has been funding have been incredibly important statewide to increase services in the home for end of life. I think their criteria was the last 12 months of life. That increase in nursing support and other support has been critical across the state. The question is what happens when the money runs out for that program.

Ms DAWKINS - How many beds in the north-west, north and south? What would it look like for a standalone facility? Three beds something like that at any given time in each area?

Mr HYNES - For our members?

Ms DAWKINS - Yes.

Mr HYNES - I would be taking a bit of a punt, I should have brought some statistics. In terms of the age cohort distribution then, yes, probably somewhere between three and 10 would be -

CHAIR - Statewide?

Mr HYNES - Yes, statewide.

Ms DAWKINS - Distributed between the three regions? It changes from year to year I would imagine.

Mr HYNES - For some reason we seem to have more of a cluster towards north and north-west than we do south. I do not know why. It might not be particularly even as you would think just on a per capita basis. We also recognise that is a significant cost and consideration going down that path. Certainly it is worthwhile for our members.

Ms DAWKINS - It would free up some hospital beds that MND patients might be using.

Mr HYNES - Yes, which is worst case.

Mr JAENSCH - May I confirm, does there seem to be commonality in the treatment needs for Huntington's and MS? So if there was a business case being developed for something like this it is not around three to 10, but it may be about your cohort, the MND cohort. Are Huntington's and MS travellers of this in terms of service needs?

Mr HYNES - We are a member of the Neuromuscular Alliance of Tasmania which includes MS, Huntington's, MND, spina bifida, there are three or four others which was around common needs, common issues, whether it was NDIS, residential, palliative care.

Mr JAENSCH - That is an alliance in Tasmania is it?

Mr HYNES - Yes.

Ms OGILVIE - As far as that alliance goes, we are talking about spina bifida and younger patients. That would cause the age cohort to be much broader than from 55 up if you were looking at some other sort of facility that could look after outside of an aged-care setting.

Mr HYNES - Yes. Perhaps to the extreme of our cohort, we have a member who is 32. We see people from about late 20s, which is quite rare, right through to 85, in terms of diagnosis.

CHAIR - You mention in your submission you use regional advisory services. Are they north, north-west and south? How does that work? You say they are funded from Victoria but are they located in our regions?

Mr HYNES - I will give you a quick overview. In about 2007 we thought there was a big gap in what we were doing as an organisation to help member. We were lagging behind the other states and territories around this thing called 'regional advisers'. It is basically a system navigator for patients and their families to understand and link into the myriad services available to them, whether social, health, palliative et cetera.

When we first started that we part funded with MND Victoria and they were quite eager to help us. It was a fly-in fly-out model for the first three years. That person would cover the whole state. Each trip she might, in one instance, go to Hobart, Launceston and the north-west et cetera. The key point of that role is to get early referrals into the services the patients might need. They don't even know they are available. 'What does palliative care do and can I access them 12 months before I know I might die?'. It is an education process as well. The other big issue for us is early access to equipment. It is a massive issue for us.

We have now turned the regional adviser position into a position that is based in Tasmania. It is based on Launceston. It is the most logical point. That person is employed one-and-a-half to two days a week to do that regional adviser model. They also travel to wherever the patients are, providing the same services I just described - linking people into services they need and doing health professional education. That is, teaching allied health professionals, GPs, nursing staff et cetera about some of the things to look out for and providing information about the disease. It is quite rate that some health professionals will come across MND and that can be a very helpful, supporting mechanism as well.

One of the key things that role does is to get early referrals to the equipment services, particularly in the community equipment scheme - it is now called TasEquip. Because our patients deteriorate so fast, they need strong advocacy. Say, there is a new electric wheelchair required and a therapist will assess the patient and then design an electric wheelchair in collaboration within the equipment scheme. The longer those delays, the more useless that piece of equipment. Their needs change so fast - and this has happened many times in the past - the wheelchair turns up and the patient is already far too deteriorated to get any use out of it.

Ms OGILVIE - How long would it take to get one built? Is that a major delay?

Mr HYNES - It depends. The time frame delay seems to have improved with the equipment scheme. The big thing is sometimes the availability of funds within the scheme, which has led us to develop -

Ms OGILVIE - Is that a government scheme?

Mr HYNES - Yes, state government.

Ms OGILVIE - State government, not NDIS? Is there any connection?

Mr HYNES - Not yet, because the cohort of patients that we are in - 30 and older - we won't start to hit that until 1 July next year, and then full roll out in 2020.

CHAIR - Within the NDIS is what you are referring to there.

Mr JAENSCH - Is there a mechanism for specialised wheelchairs? It sounds like they each have to be custom built to a need, over time what happens to that equipment? Does that cycle back in to the system to be recommissioned for people?

Mr HYNES - Yes, with bits taken off, seat adjustments, height adjustments, et cetera.

CHAIR - The base of the electric wheelchairs, it's just the seats and the operational devices and that can be done now here in the state?

Mr HYNES - Yes, that is right. The question is the total pool of funding available - which seems to be on a process of draining down funds over the financial year - to the point at which some requests for equipment have not been possible for our members towards the end of the financial year. We set up internally an equipment donation scheme where if members apply to us and there is a gap of a funding amount for their equipment then as a board we can consider that request and donate funds to the member to make up the gap. In some cases it is highly specialised speech equipment, for instance, that a member might want that the equipment scheme may not be able to provide because of the sheer cost. We will also consider those and contribute to the member as well.

Ms OGILVIE - Is there a gender divide in diagnosis of MND?

Mr HYNES - There is a slight skew towards males.

Ms OGILVIE - It is an inherited condition?

Mr HYNES - Ninety per cent of MND cases are what they call sporadic, which means they have no idea.

Mr JAENSCH - Spontaneous.

Mr HYNES - Spontaneous; 10 per cent are hereditary, familial, and of those 10 per cent if you are in that hereditary stream then you have a 50 per cent chance of getting Motor Neurone Disease.

CHAIR - Whether you are male or female? It's not like Huntingtons?

Mr HYNES - No.

Ms DAWKINS - Is there still pain associated with end of life care and pain management? Is it the same as it would be for conditions people usually die from?

Mr HYNES - Is there pain management?

Ms DAWKINS - Yes.

Mr HYNES - Yes, I think palliative care services generally, what we find across the state, are very good at symptom management and pain management, particularly end of life. Whether that is the drugs or the secretions in the saliva for our members, because they are just struggling so much with that. Also there is assistance with breathing through mechanical ventilation and tubing, et cetera, if the patient desires. Also, at very end of life stage pain relief is provided so that they are not suffering from the sensation of choking, et cetera.

CHAIR - Are there areas of palliative care that you would like to see handled differently for your particular cause?

Mr HYNES - What we would love to see is a consistent, multi-disciplinary approach to palliative care in the north, north-west and south. Off their own bat, Palliative Services in the south coordinate a multi-disciplinary MND meeting.

CHAIR - Is this the Specialist Palliative -

Mr HYNES - Specialist Palliative Care Services in Hobart. They regularly, probably every one to two months, every quarter at worst, will review their MND caseload across speech pathologists, allied health, nursing, palliative care positions, et cetera. They talk about each case and discuss what the needs are. This is really important because it is a global picture. It also then helps to inform discussions around end of life planning. The speech pathologist can say, 'I've had a conversation with Mrs Jones and I don't think she wants peg or tube feeding' or something else, and that is important.

CHAIR - Are suggesting it does not happen in the north or north-west?

Mr HYNES - Historically, that does not happen in the north and north-west, as far as we are aware, with the specialist palliative care services, and by that I mean having a MND case conference and determining what the needs are. That would be a huge step for us.

Ms OGILVIE - It is good to have the information, thank you. We're getting similar themes coming through from many different perspectives, including those who have cared for a patient, and a lot of it is around similar conversations about good access, multidisciplinary approaches, sharing of information and how best to do that so it does not lay a process burden on people. So there are similar themes coming through, for your information. It is very good have it from your organisation.

Mr JAENSCH - The other thing underlined in your submission and comments is that the responsiveness needed in a system like this is time critical so that early in diagnosis, while the person has the ability to communicate autonomously while dealing with a known trajectory, they can get this planning into place quickly. You mentioned treatments that may slow progression. It sounds like that is not significant.

Mr HYNES - There is one drug on the market called riluzole that would extend someone with MND's life by a maximum of three to five months. The other key thing about our role is contributing heavily to research to continue to find cures and treatments.

CHAIR - Your contribution is really helpful and we appreciate your time because we need to get a global picture of the issues and having something like this and your broad breadth of knowledge of this specific and demanding need is really helpful. I appreciate your time and thank your organisation.

THE WITNESS WITHDREW.

Dr JACKIE HALLAM, POLICY AND RESEARCH OFFICER, AND **Dr BECKY SHELLEY**, CEO, ALCOHOL, TOBACCO AND OTHER DRUGS COUNCIL, WERE CALLED, MADE THE STATUTORY DECLARATION AND WE EXAMINED.

CHAIR - Thank you for coming before us today. 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 to give evidence to a parliamentary committee, to speak with complete freedom without the fear of being questioned or sued in any court or place out of Parliament. It applies to ensure that the Parliament receives the very best information when conducting its enquiries. 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 proceedings. This is a public hearing. Members of the public and journalists may be present. 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 that evidence. Would you like to make an opening statement?

Dr SHELLEY - I will refer to Jackie to do that as she prepared the submission. I only started with the ATDC last Monday.

Dr HALLAM - We would like to flag first up that data is showing that people who use alcohol and other drugs are aging. There is a large group of people moving through who are going to create issues for the workforce. They are already creating issues for our workforce, but that will impact again on the care teams.

For these particular clients, of course, alcohol use is a mainstream issue, but there are other drugs used as well. There are a lot of people at I guess you would call the pointy end who experience issues as well as their alcohol and other drug use, issues like mental health and other health and welfare issues. People do not have stable homes, they do not have jobs and they have an unstable family life and just a lack of support.

What that means is that our workforce which deals with people with alcohol and other drug issues are also having to deal with all these other issues. As these people move through and get older and develop end-of-life problems and issues and so on, these are the sorts of complex clients, I guess you would call them, our care teams are going to have to start dealing with even more again as those people using alcohol and other drugs get older. That means our workforce is constantly having to stay ahead and be connected with other people who provide mental health services and people who deal with homelessness and all those things I mentioned, so it is about those care teams being worked in with other sectors. That is something we would like to flag.

One of the key points that is mentioned is the need for a nationally consistent advanced care system. I spoke to a palliative care educator this morning and she was saying there is a need for a national database. This particular group of clients, because of their unstable nature and how they live and so on, move from state to state and area to area. Being able to not have to go through all that again and talk about their end-of-life issues and care and so on, a nationally consistent system - and I think that is in my research - is being advocated for and called upon by loads and loads of people. That is not just us obviously saying that. You will obviously probably have heard that over and over again, but definitely in terms of our group of clients, that is a real need.

The other thing is the policy infrastructure to support that group of clients. As I mentioned before, it is about them being connected to other sectors. We have an ongoing issue with our clients who face stigma around accessing pain management. If they are identified as substance users people can often shut down and turn them away or not treat them in the same way as people who are not identified as substance users. Pain management can feed into alcohol and other drug issues because you can be dependent on a pain medication and that in turn can create a substance use issue. Then you get to the end-of-life stage and it is about whether they are treated in the same way. I am not sure whether there is policy around that and whether there is a need for workers to have their capacity raised and their values looked at with regard to that. We believe at the ATDC that everybody has the right to die pain-free and be treated in an equal way. That stigma issue is a big win in our sector and this is with people who are well across all the issues with alcohol and other drugs. We face it, so I am sure the care teams might have to have their capacity raised too. Is there anything else I need to add?

Dr SHELLEY - Our sector deals with a cross-section of issues from tobacco and alcohol through to illicit drug use. One in eight people smoke daily and one in five experience alcohol-related harm in their lifetime, so we would never want to miss an opportunity to emphasise the need for prevention, early intervention and support to try to reduce the harm caused by alcohol, tobacco and other drugs. As Jacquie alluded to in her opening statement, a cohort of people - whether they are baby boomers or other people who have smoked and drunk - are moving through the service system. Knowing the demographic profile of Tasmania, I think it is a timely inquiry and these are issues policy makers in the sector need to have an eye to in ensuring that the right investments are made at the right time to support and work with people as some of the impacts of those earlier life decisions start to manifest themselves in the health system and within their own processes.

Mr JAENSCH - Thank you very much for your submission and coming in today. When you refer to this ageing cohort, does it have a long tail to it or are we recruiting just as many young people into alcohol, tobacco and other drug use? Or is the whole cohort moving through like the baby boomers are?

Dr HALLAM - We saw drug use in Australia really pick up in the late 1960s-70s, so it is about people who were obviously in that early stage of taking drugs. It is the baby boomers, those in their fifties and sixties and so on. In terms of the amount of people continuing to use, that is fairly consistent. We have surveys that go back to the 1980s and rates of drug use are fairly consistent, but in people at this point who are probably 70-plus, they are certainly using alcohol but not cannabis and other sorts of drugs.

Mr JAENSCH - Secondly, do you have any data or information about how many people who have alcohol, tobacco or other drug dependencies are self-medicating or treating issues? When we are talking about palliative care, pain treatment and some of those other things, how many of the people your sector sees are doing that for themselves through their drug and alcohol use?

Dr HALLAM - Do you mean self-medicating for pain?

Mr JAENSCH - For pain and maybe even degenerative conditions, but they are dealing with it with drugs rather than medicine?

Dr HALLAM - I don't think there is any data specifically on a population level that will pick that up. We have rates of use and there is certainly the intersection established between pain management and alcohol and other drug use and then substance use, but there are no national surveys and no Tasmanian data that looks at it on a population level.

Mr JAENSCH - I am thinking of the stigmatisation you were talking about before and it would be very interesting to know how many people you deal with are managing a mental health issue or a chronic health issue through self-medication.

Dr HALLAM - That is a topic that comes up in conferences and presentations and is picked up by doctors and academics. It is a big theme which comes through the literature but we don't have any national data to say, for example, 30 per cent of drug users are from that. I guess you could look at drug use statistics and see that morphine, methadone and other opioids which are used for pain and you can look at the rates of that use and then from that you could kind of, but there's no national data. But it is an established link and there are lots of academic papers on it.

Ms DAWKINS - You were saying clients move around a lot, some suffer from homelessness and lack of an anchor to the world. There is also a lack of engagement with the kinds of ideas that advance care directives would bring up. Do you feel your clients are able to engage with the idea of an advance care directive?

Dr HALLAM - A lot of our alcohol and other drug workers have to advocate for clients, so it's that whole issue of speaking for somebody and giving consent. When I spoke to the palliative care educator this morning she was saying there is a huge issue in getting people's wishes written down. That is an issue if they are moving around, so that is very much a key issue for people experiencing those issues and being able to provide consent and express clearly what they would want to happen.

Ms DAWKINS - Clearly there is a stigma attached to people who use methadone in the community. For somebody who has come off heroin or morphine and been prescribed methadone for many years, would they use methadone as an end-of-life drug or would they need something else?

Dr HALLAM - There is methadone syrup and physeptone, which is the slow-release tablet form. The teams would only use the tablet form for palliative care. When you're at that end-of-life stage, it is about having as many tools in your toolbox as possible. I don't think we are talking about syrup at this point, we are talking about the tablets.

Ms DAWKINS - As an aside, I had a constituent call last week who had been given suboxone instead of methadone. I hadn't heard of that before. Is that something we can use in place of methadone in the same circumstance?

Dr HALLAM - I'm not sure, you'd have to ask someone who has a clinical background. I think that's more for people who have an addiction and are wanting to come off drugs rather than a pain management thing. I think it is at very low doses, I am not sure.

Ms OGILVIE - We have had a lot of evidence given today, in particular around hospice practice in the community and at home. It seems to me to be entirely heartbreaking that we have a group of people who do not have a home in which to die. For me, that seems to be at the very top of the pyramid.

Dr HALLAM - Absolutely.

Ms OGILVIE - Could you give me your full barrels on that topic?

Dr HALLAM - It is not just about a home. It is about having people that have an ability to get to appointments, that are able to access medications. I am not sure whether medications with the palliative care team are free, they probably are but I am not actually across that.

Ms OGILVIE - I think it is GP driven.

Dr HALLAM - I do not know what the actual cost is. If there is a cost, we have our clients who struggle to get the $2.50 or $3 or $4 to get methadone syrup. When you come to that stage and you do not have family support, you do not have a house, you do not have a car, you do not even have a phone and maybe you do not even have friends and you are isolated. The lack of all those things that mainstream people take for granted will reduce the ability of care teams to do their work.

Ms OGILVIE - And to find the person.

Dr HALLAM - Yes, that is right.

Ms OGILVIE - Do you have some views around what we could do apart from the obvious, finding homes and sorting all of that out which is a challenge? Is there something that we can do as palliative care providers - stepping into those shoes - that would be more of a reaching out to those people? Is there something you could ask for?

Dr HALLAM - I think it is what is about workforce development. It is about getting care teams to be expecting that there will be a bunch of people with these sorts of issues. It is about making sure that they are hooked up to other services, that they know how to deal with someone who has a mental health issue or who has a homelessness issue. Perhaps it is about flexible funds to deal with issues as they arise because everyone has their own particular case.

Dr SHELLEY - There are good models in terms of assertive outreach that work within the housing and homelessness sector or youth services. Perhaps there is a model that could be translated and adjusted in terms of this particular group. As Jackie said, the effective of those models requires that staff are adequately trained to respond and because often there may be comorbidities. There are perhaps mental health comorbidities or other comorbidities where having that assertive outreach function to develop the trust and relationship and actually have meaningful engagement does require an investment. The investment would be both in resources but also in skill development, perhaps in addition to the mainstream hospice or outreach services you might be contemplating.

Ms OGILVIE - There might be a particular program, yes.

Dr HALLAM - One other point there would be - one of the key things for the workforce is looking at stigma, your own practice and your own values when it comes to people that use alcohol and other drugs.

CHAIR - I have a question in regard to the evidence we have received from hospice at home where they provide kits, which involve or include S8 drugs to people in their last stages of life. Could you give me some insight? Do you see if there is a risk in our community from your perspective, having these in homes? How do you see the people you advocate for in dealing with these drugs in their home? Are they suitable candidates? I do not want to put words into your mouth but I am interested to hear your perspective on this.

Dr HALLAM - I think there is a balancing act required in that. There is a risk people will divert drugs. I am not sure whether that is where you were going with that?

CHAIR - I don't know.

Dr HALLAM - There is a risk of that, but I guess it is about providing the appropriate care. I am not sure what else I can add.

Dr SHELLEY - I think there are risk mitigation strategies that are used for methadone and other treatment that adds to this cohort.

Dr HALLAM - Absolutely.

Dr SHELLEY - There would be models to manage risk. I think that could be developed, in response to the particular risk Dr Hallam has identified. Again, I go back to the point we made earlier. The illicit drug use in palliative care question is so much. The alcohol and tobacco issue is sitting here. Generally I think the risk is low. If you had a cohort for whom you need to devise a particular mitigation strategy then that can be done.

Dr HALLAM - We also have regular data coming in about use of those sorts of drugs - morphine and so on. There are a couple of Tasmanian studies that go on each year where we monitor use and so on. We would be able to see across time whether use was up, down, wherever. There is a monitoring system, if that makes sense.

Ms OGILVIE - From my perspective it is really interesting and helpful to hear about that cohort that is moving through. Picking up on Mr Jaensch's comment, I presume we are doing a better job of making sure people stay off the drugs and alcohol in the generation coming through, hopefully. Maybe times have changed. I don't know.

Dr HALLAM - We will have to wait and see. It is all fairly stable in terms of rates of use. The main difference is at this point if you look across everyone right now, the baby boomers are leaving and using other things apart from alcohol. Older people will use alcohol but cannabis and all the other drugs are baby boomers onwards and those rates are stable.

I will say not many people use illicit drugs. Hardly any of them. We are talking about 2 per cent who would use those sorts of drugs. Whereas, you are talking 40 per cent and more using alcohol and tobacco.

CHAIR - Thank you very much.

<u>THE WITNESSES WITHDREW</u>.

Ms COLLEEN JOHNSTONE, PALLIATIVE CARE TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Welcome to our hearing today and thank you very much for your submission and attending here today. This committee hearing is a proceeding of parliament, which means it receives the protection of parliamentary privilege. This is an important legal protection that allows individuals, giving evidence to the parliamentary committee to speak with complete freedom without the fear of being sued or questions in any court or place out of parliament. It applies to ensure the Parliament gives the very best information when conducting its inquiries. It is important to be aware that this protection is not accorded to if statements that may defamatory are repeated or referred to by 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 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 that evidence.

Ms JOHNSTONE - I am the general manager of Palliative Care Tasmania, the peak body for palliative care in Tasmania. We are a member of Palliative Care Australia which is the national peak body for palliative care. My organisation has been around for about 20 years. We have a council which is comprised of professionals in the palliative field. Our role is primarily to advocate for high-quality palliative care services for all Tasmanians. We also provide education across the community. In the last 18 months we have educated around 13 000 Tasmanians, including those living on King and Flinders islands.

We are very interested in and support this parliamentary inquiry. If anything, it helps to raise awareness in the community about palliative care. Before we go too much further, I want to clarify that, for my organisation, the terms 'palliative' and 'hospice' mean the same thing. The term 'hospice care' was coined initially in the UK and 'palliative care' was coined in Canada because there were some particular religious connotations around using the word 'hospice', so for my organisation they mean the same thing.

We are very interested in the issues this committee is looking at, particular around advance care directives. I will go through some points in the submission and then am happy to answer any questions. In terms of advance care directives, in our opinion and also in some of the national organisations and groups we are party to, we believe that Tasmania has perhaps the most contemporary advance care directive system in the country. In Tasmania you have the ability to plan for diseases that you don't have, so as a fairly healthy 41-year old woman I can plan for the type of care I want when I am dying, even though I have no life-limiting illness.

Advance care directives are not, as we know, in Tasmanian legislation. They have some protection under common law, however as we understand it this has never been tested in Tasmania. It certainly has in other jurisdictions like New South Wales and thus far in those jurisdictions the advance care directive was found to stand up.

We have been advocating nationally, along with other palliative care peak bodies and Palliative Care Australia, for nationally consistent advance care directives whether they are legislated or not. Particularly the use of language is confusing and the fact that if I move to Tasmania, as many Queenslanders do to get away from the heat when they are getting older, if I do an advance care directive in Queensland it has no basis in Tasmania. Just like years ago when electricians and plumbers were nationally recognised with their licensing, we would like to have that national recognition with advance care directives.

There are some issues which would provide more certainty to the community if advanced care directives were legislated, particularly for medical practitioners because there is some confusion, particularly with GPs, about an advance care directive's legal status and concerns about any legal protections afforded to medical practitioners.

With the work that we've been doing we find that advance care directive knowledge is not common across Tasmania. For us as an organisation we call the advance care directive the icing and having the conversation and increasing your awareness about dying and care options available are the cake. We tend to find people are very happy to participate and have a piece of the cake, but they do not necessarily know about the icing on top.

Other issues around advance care directives is confusion over a substitute decision-maker or as the advance care directive asks, a person responsible and the legal status of that person responsible compared with the formal process through the Guardianship and Administration Board of appointing an enduring guardian.

The other issue, too, particularly in the medical system is that most hospitals, GP clinics and other health providers are still asking for people to name a next of kin. A next of kin has no automatic legal status under guardianship law in Tasmania. It becomes very confusing if a person has appointed an enduring guardian or has nominated a person responsible but they are being asked for their next of kin and medical practitioners are directing questions to that next of kin if the next of kin isn't the substitute decision-maker. There needs to be some clarification around that.

We also tend to find through our work, particularly with some general practitioners, that they are not appropriately trained and don't really have the skills to engage in conversations with their patients about dying. The average GP sees around 30 patients a day and one of whom might be someone with a life-limiting illness, and at the moment there is no financial incentive for GPs to sit down and do an advance care directive with a patient. For example, if you have a mental health issue the GP can do a mental health care plan and that can be bulk-billed back to Medicare. We would like to see is the same sort of process applied with advance care directives, so that the GP can spend that time with you and bulk-bill that back to Medicare.

Another important issue is that with GPs and medical practitioners is our western society is focused on cure and a lot of medical practitioners aren't very good at diagnosing death, and if they are they are not very good at communicating to the person that they are going to die. We are advocating for more education, particularly so that when medical practitioners first realise there is no hope of cure that the advance care directive is done, but also medical goals of care are correctly completed. The most important thing from our perspective is ensuring the community has access to information and education so they are aware of what end-of-life care options there are, that they are aware palliative care is not only about the last few weeks of death in a medical facility. It is a lot broader than that. With high incidents of chronic disease in Tasmania, people can be receiving palliative care or care under the palliative approach for years before death. Most palliative care is done in the community. It is not done by medical professionals; it is done by husbands, wives, children, local community organisations, the local GP and local pharmacist. Educating the community about that is very important because that then helps them understand the current environment and have those conversations with their loved ones.

The other big issue with advance care directives is there is no central repository, so the onus is on the individual. That has a lot of risk and pitfalls. If I lodge my advance care directive at the Royal Hobart Hospital and something happens to me on the north-west coast, that doesn't mean the North West Regional Hospital will have access to my advance care directive. There is also an issue for emergency services. They don't have access to advance care directives and with the current system paramedics are only provided with an address. They are not necessarily provided with the individual's name, so even if they were given access to advance care directives, they don't know who they are going to treat. They don't know the person on the floor is the person the advance care directive is related to. That is a very big issue.

The other issue with advance care directives is that we strongly support the Guardianship and Administration Board's hierarchy for determining substitute decision maker. We like the fact they're not concerned about blood family relationship; they are more concerned with the connection between people. That is particularly important for members of the LGBTI community, but also for those people who are homeless and might be disengaged from their families.

The only other thing I would say is that in Tasmania at the moment a person must be 18 to complete an advance care directive. We believe that age should be removed. We believe that if you have the mental competence and can be supported in your decision making you should not be subject to a mandatory age. That is relevant for young people, particularly teenagers. At the moment they can have a say and some control over their care, but they can't do an advance care directive, so we would like to see that changed.

That segues nicely into the administration of medical treatment to minors. At the moment there is no fixed age relating to consent to accept or refuse medical treatment. My organisation does not support the mandatory setting of a minimum age for young people. Many young people, particularly teenagers, know more about what care they want than the adults treating them, and if they do not, there are supportive parents, family, carers and medical practitioners around them who can provide support to make those decisions.

When you are dying, one of the most fearful things is loss of control. That is particularly important to young people. They may have already had to give up playing cricket or social access to their friends through school or sports, and to then take this control off them, we just would not support that.

Because of Tasmania's demographics, we do not have a lot of young people receiving palliative care. The majority of young people who have life-limiting illness are treated in Melbourne and Sydney. We have heard medical practitioners at the Royal Children's Hospital in Melbourne are telling families that there are no paediatric palliative care services available in Tasmania, which is erroneous.

Even though we do not have a named paediatric palliative care service, the three specialist palliative care services across the state provide paediatric services, as does the Hospice at Home program, as do community nursing. Also, young people are supported through the paediatric wards across the state and also the oncology units. There are also organisations like CanTeen and Camp Quality, and there are bereavement support organisations like Bears of Hope and The Compassionate Friends that provide support to bereaved parents. That gets back to education that there are the services available.

It is ensuring people have the information and ability to access those. Our organisation has educated a lot of people across Tasmania, and held forums for bereaved parents. One of the biggest issues for bereaved parents is that many of them feel dumped. That is their words, not mine. They feel dumped after their child has died. If a child has not been receiving care from one of the specialist palliative care teams, it is not automatic that there will be follow-up provided to the parents and the carers.

Palliative care is not just about looking after the person dying, it is looking after the support network around them. If those young people are being seen only by oncology units or paediatric units and the specialist team has not been called in, follow-up may not necessarily occur.

I have had mothers tell me that when their child has died they have been given two hours with the child down here at the Royal Hobart Hospital, and then they have had to put all of the possessions of that child into a wheelie case and they have wheeled that bag out of the hospital and not seen staff, not had follow-up, not known where to go. They have just been handed a stack of brochures. From our perspective, grief and bereavement support and access to that support is an issue right across the palliative care spectrum, but particularly for bereaved parents. We think that is a big gap.

Ms OGILVIE - I think it is a big gap, too.

Ms JOHNSTONE - As I touched on before, administration of medical emergency treatment is very complex. There is no repository for advance care directives, so therefore at this stage we support the approach that paramedics take where they aim at preserving life. Until such a time that they have access to the information that they need, they must adopt the approach of preserving life.

Mr JAENSCH - Particularly when it is time-critical and you have to make decisions fast.

Ms JOHNSTONE - That is right. In cases where people are dying at home with life-limiting illness, and emergency medical treatment is required to ensure that person is comfortable - it might be administering pain relief - we strongly recommend that the treating doctor completes that medical goals of care, and that the person in charge of care for the dying person has that on them when the paramedics arrive and provides that to the paramedics. That is the best that happens at the moment in Tasmania. It is obviously how the paramedics approach that from then on. As I said, we support the fact they need to focus on preserving life in those situations. I understand Professor Ashby is appearing before you this afternoon and he would be able to answer this better than I, but from our knowledge it is not common that a dying person would suffer an emergency event that required resuscitation. We don't know the figures on that but we know it is not common.

In terms of other matters, from our perspective we think Tasmania has exceptional palliative care services compared to other jurisdictions, but as I said before, it is important for policy makers and the community to understand that, just as with mental health, the majority of palliative care occurs in the community and is provided by the community.

The main issues that impact effective service delivery in Tasmania, from our perspective, is lack of community understanding about palliative care and the service options that are available. There is also a lack of community understanding about death literacy, how to have a conversation with your loved one and advanced care planning. There is a lack of communication between service providers. There are insignificant grief and bereavement services particularly, as we said, for bereaved parents. Southern Tasmania lacks the scope of regional palliative care suites that northern Tasmania has. As we know, in Tasmania 70 per cent of us want to die at home, whereas nationally only 14 per cent of us do. In Tasmania under the Better Access to Palliative Care in Tasmania program we have raised that to about 26 per cent and it is still rising. If they cannot die at home people want to die in their communities. In the north and the north-east people have access to about 10 palliative care suites within their communities. In the south and in the north-west we do not have that same access.

In terms of workforce, the specialist services have an ageing workforce, however community-driven palliative care does not have an ageing workforce; it is a younger workforce. With an increase, particularly in Tasmania, of complex chronic illnesses, we need to ensure this workforce maintains and receives education and increases their skill set. Also in Tasmania we have very limited support for carers. That is a national problem. We know nationally carers are worth billions of dollars to the economy but, again, in terms of carers for the dying, there are not enough support services available for those people.

As I mentioned earlier, there needs to be more training of medical professionals in terms of diagnosing death and how to have conversations with their patients about dying. There seems to be a perception that, using cancer as an example, it is either chemotherapy or palliative care. Palliative care and curative options walk hand in hand. It shouldn't be one or the other, it should be both. We know medical specialists are not referring their patients to palliative care early enough.

Ms OGILVIE - We have heard quite a few comments about that.

Ms JOHNSTONE - As we know, palliative care is not about prolonging or hastening death, but we tend to find the more quickly people are referred to palliative care the better their pain is managed and the better their psychosocial needs are managed, and they tend to live longer because their care is under control.

Finally, to reiterate, we have provided education to more than 13 000 Tasmanians in 18 months. My organisation has no funding from 30 September. The federal Government has not committed to funding us. We receive no funding from the state Government either. We do not even receive peak body funding.

Mr JAENSCH - It has been running for 20 years, so what has kept you going?

Ms JOHNSTONE - Before three years ago, we were running a kitchen table organisation. Once we got better access to palliative care funding we mobilised and formed a business entity. With us closing our doors on 30 September, we are the only organisation in Tasmania that provides palliative care education to the community. We have also educated 1400 medical professionals in the last 18 months and all of that will end. We had a meeting with the Commonwealth and they are in the process of redoing the national palliative care strategy, they are revising it and are holding public forums right across the country. In the public forum in Tasmania which was held in Hobart, it was very clear the only reason Tasmania has been able to meet the priorities of the national palliative care strategy is because of the Better Access to Palliative Care in Tasmania program. Without that funding and support, it is unlikely we will be able to meet any new priorities from a revised version of that strategy.

Ms OGILVIE - I was grateful to hear you talk about the big gap regarding bereaved parents which we have all been trying to work on from a community perspective. I was interested to hear you say the Victorians are saying there is no palliative care for the neonatal and a conversation needs to be had around that. How do you think we would be better able to communicate in that neonatal setting where things can go from joyous to horrible very quickly that the mum or parents have a right to call for or get access to palliative specialisation? Are we relying on the nursing staff who are a bit like the paramedics in that there is a culture of keeping everybody alive, but there are circumstances in which you should, could and should be allowed to stop and let nature take its course? Do you have some views around the communication there? Is it service access?

Ms JOHNSTONE - That issue is not specific to neonatal, it happens in paediatric wards and even for adults in oncology. There appears to be a culture of holding onto the patient and not recognising and perhaps not having the education to know when to call in specialist palliative care services. It is very interesting that you often hear commentary that talking about death is morbid and taboo and people do not want to talk about it, but that is not our experience. The people who do not want to talk about, in our experience, are the medical professionals. The community wants to engage. I think sometimes medical professionals believe that once they start using the words 'palliative care', that means the medical system has given up and all hope is lost. They do not necessarily recognise that by bringing palliative care in it can provide that type of care and support to make the person dying comfortable - whether it is a baby or an adult - but they also support the broader family. Ms Ogilvie, it is completely an issue about communication and education because the services are there. It is the fact other services are not calling them in at the appropriate time and they need to be educated about that.

Ms DAWKINS - Do you think we can have a conversation around the legal status for the advance care directives without talking about voluntary assisted dying?

Ms JOHNSTONE - Palliative Care Australia is currently working on their national euthanasia and assisted dying policy, but from my perspective palliative care and euthanasia are separate issues. There seems to be a thought that euthanasia is a natural end to palliative care and that is not our perspective at all. I would prefer to keep those separate from my evidence today, but I certainly understand that within the community voluntary assisted euthanasia is something that many of us are interested in and we need to get more information about.

Again, from my perspective as the general manager of the peak body, what we find is that when the community starts talking about euthanasia or assisted dying they start to educate themselves more about what care options are available in the community and what palliative care is. I have given a very long non-answer to your question.

Ms DAWKINS - It is about the legal status, isn't it? If we conflate the issue by even trying to talk about the legal status would the national framework then be the best first port of call to try to strengthen the directives?

Ms JOHNSTONE - Certainly, I think so. I know that the Australian Department of Health is currently looking at comparing all of the advanced care directive systems across the country. I think they are looking to see how they can increase consistency.

Mr JAENSCH - Who is doing that?

Ms JOHNSTONE - The Australian Department of Health. I do not know whether down the track we might see some type of model legislation. The only concern that I would have as I said earlier we lead the way in advanced care directives and I would not like to see us drawn backwards. For example, apparently in Victoria you cannot plan for an illness you do not have. You can't say, 'If I get dementia, I want this care.' The problem is, when you get dementia you can't say it.

Ms OGILVIE - It's too late.

Ms JOHNSTONE - In Tasmania, I wouldn't like to see us drawn backwards.

Ms OGILVIE - We don't want to go backwards.

Mr JAENSCH - Again ours aren't backed by legislation and are not registered anywhere.

Ms OGILVIE - There are improvements and good things.

Ms JOHNSTONE - Yes.

Mr JAENSCH - Colleen, thank you very much for your advocacy for this area and the hard work you are doing. I have been hearing about your activities over the last fortnight or week around the state. Thank you for that.

In that education and in that conversation going, anecdotally in rural communities - like the one where I live - statistically, we have reported high levels of suicide in older men. I am supposing that for some of those people they are considering that as a way out when they have terminal conditions added to a range of other issues. Have you encountered or deliberately planned to put a message out that palliative care provides options that people might be unaware of and who might be resorting to suicide?

Ms JOHNSTONE - We have not specifically targeted suicide. We look at suicide in the context of grief and bereavement. We have not looked at suicide in terms of people using it as an option instead of euthanasia, because euthanasia is not legalised.

Mr JAENSCH - Or prolonged treatment and a long, lonely end of life in pain.

Ms JOHNSTONE - What we do in terms of our community education is we provide the information about what palliative care is and what services are available in communities, the importance of having the conversation with loved ones, the importance for people to know what your wishes are and we talk about grief and bereavement. We statistically do not know the rates. It is, as you said, anecdotal. We don't know the rates that people are utilising suicide as an option. It is certainly an area that we need to look at in more depth. It is the same with homelessness, as we heard earlier. Under the Better Access to Palliative Care in Tasmania Program we had specific areas that were contingent on the funding that we had to educate in and that unfortunately wasn't one of them.

Mr JAENSCH - You said 'unfortunately' there. The statistics I have heard reported back through suicide prevention programs rate men in their eighties or over 85 is the biggest age cohort in what are, sort of, reliably reported as suicides. If you were pitching your services and approach afresh, might a diversion from suicide be an area that you would legitimately look into?

Ms JOHNSTONE - Certainly we would and at the moment we work with men's groups. We work through men's sheds, we go through Rural Alive and Well, and other very small not for profit community organisations. One of the issues in particular in the north-west, we think, is that there are not enough places for respite on the north-west. The north and the north-east are very well serviced. The south is okay for a population basis but up in the north-west and the west we think that there could be more done in that respite area.

I wonder whether if there was better access to respite and also the support for carers because - again anecdotally - I have heard across Tasmania, only once or twice, that older people once their partner has died that can have an impact on suicide rates as well. It is about that access to the bereavement support.

Mr JAENSCH - If there was a service that wrapped around a bit more and provided support for a person who is dying and their supporting carer and then followed through to that bereavement grief and assistance then that might be a way.

Ms JOHNSTONE - I think so and having that formalised respite availability. On the north-west coast we have tried to run what we call 'carer days' so that carers can come and get a little bit of the information but have that informal peer support available. Again, the issue we find is that there is no one to look after the dying person so they are not freed up to be able to attend these types of events that we offer. It really gets back to the fact that our support for carers is really abysmal.

We have great organisations like Carers Tasmania but again Carers Tasmania is not solely focused on carers who care for the dying. We really do need to look at the support we have available for carers.

CHAIR - Is an advance care directive similar to a will in that one has to find the last version of it? Do people have multiple versions of this? Is that a possibility, and how is it dealt with?

Ms JOHNSTONE - We encourage people - just like with a will - after any life-changing event to refresh it so it is the most recent copy of your advance care directive. Like we said earlier, the problem is the onus is on you to lodge it with your GP in hospital. Please do not advise anybody to put any end of life care wishes in their will because it is too late.

CHAIR - Is there guidance out currently for the responsible person in an advanced care directive? How do they learn to advocate for the person that they are responsible for?

Ms JOHNSTONE - The only real formalised education and training is the stuff that my organisation does. We have comprehensive information packages. We go out and talk to communities. As I said earlier we go to King Island, Flinders Island - everywhere. We talk about what being a 'person responsible' means, the importance to have the discussion with your person responsible. You need to make that person is comfortable before you nominate them as your person responsible, and that you have confidence that they will be able to advocate for you if you no longer can. Without our funding there will be a gap. There will not really be anybody to provide that. We have seen the popping up of very small groups of people who are interested in this area have been popping up, but they have no training. For example, there was one event over the weekend where the people who were taking it did not know the difference between the power of attorney and an enduring guardian. We are the only ones in Tasmania that provide that education.

Ms OGILVIE - Would you like the committee to take seriously on board the issues which you have expressed around the funding? What might that look like if you were to ask for the funding that you needed to run your organisation for the next five years? I will just get you to sketch it really quickly for us.

Ms JOHNSTONE - We need around $550 000 to $600 000 a year to continue doing what we are doing. We provide the three types of education: palliative care, death literacy and grief and bereavement. We design it for the communities that we are in. We do the bottom-up approach, not the top-down approach.

I have closed my north-west office. I am about to close my Launceston office, and I am closing my Hobart office because we just do not have the funding. Talking about workforce development, the knowledge of my staff will be lost, it will be gone. It is not something that you can just pick up reading a book.

For us to continue doing what we are doing - we have also been recognised nationally as leaders in this field. We have the ACT and South Australia knocking on our doors for them to use a similar model and for us to skill them up to do what we do. However, we cannot do that because we do not have the funding. It will be completely lost. For around $550 000 a year we can continue doing this.

The good thing is, talking in a purely economic term, the more we do this education, the more people talk about what end-of-life care they want. Most people want to die at home. It keeps people out of the hospital system. It saves money for emergency services. It saves money in emergency departments. We have fewer people admitted to hospital, so overall we end up seeing fairly significant savings across the health system.

CHAIR - Thank you very much, Colleen; we really appreciate your contribution today.

THE WITNESS WITHDREW.