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THE HOUSE OF ASSEMBLY STANDING COMMITTEE ON COMMUNITY DEVELOPMENT MET IN COMMITTEE ROOM 1, PARLIAMENT HOUSE, HOBART ON MONDAY 12 SEPTEMBER 2016

INQUIRY INTO PALLIATIVE CARE

Mr VICTOR STOJCEVSKI, SENIOR POLICY ADVISOR, CORONIAL DIVISION MANAGER, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED

CHAIR (Ms Rylah) - Welcome. This hearing is a proceeding of Parliament. That means it receives the protection of parliamentary privilege, an important legal protection that allows individuals giving evidence to a parliamentary committee to speak with complete freedom. This protection does not apply outside this hearing. This is a public hearing, but should you wish evidence to be heard in camera you must make this request and explain why prior to giving that evidence

Mr STOJCEVSKI - For the purposes of the committee, I will make an opening statement about the nature of the coronial jurisdiction. It is jurisdiction that organisationally sits within the Magistrate's Court of Tasmania. The Coronial Division sits within the Magistrates Court of Tasmania. The head of jurisdiction is the Chief Magistrate of Tasmania.

We have four coroners currently in Tasmania. One of them is a full-time coroner who has been delegated by the Chief Magistrate with powers of a chief magistrate - that is Coroner Olivia McTaggart. We have a part-time coroner in the north of the state, another part-time coroner in the south of the state, and one other part-time coroner in the south of the state. There are four coroners all up in Tasmania who divide their case load - about 550 to 600 cases per year.

In the 2014-15 financial year we had 542 deaths reported to the coroner. We had 10 inquests held in the 2014-15 financial year. We had 489 cases closed in that financial year. Each coroner roughly has about 100 cases. Of those coronial inquests and investigations, I will give some of the main ones. Thirteen of those were drowning deaths; 29 were drug over-dose deaths; 31 were deaths by fall. Two of those deaths were homicides. Seventeen were deaths in a hospital setting; 242 were deaths regarded as natural. They are mostly as a result of a heart attack or heart disease or enlarged heart or pneumonia. They are sudden deaths that occur in a natural state. We had four SIDS deaths; 71 suicides in 2014-15 and we had 34 deaths by vehicle crash. That is the nature of the work that usually and predominantly comes before the Coronial Division. The functions of the Coronial Division are laid out in the Coroners Act 1995.

Ms OGILVIE - Part of the reason we have had this inquiry is to look at issues around palliative care and end-of-life decision-making, particularly in a context where we know not everybody dies in hospital; people are able to die at home and in various other settings. Would you, in the scope of that thinking, state when the Coroner would become involved or when a report would be made to the Coroner? You have sketched some numbers here - around 600 cases per year reported. That seems a lot to me. Of those 17 deaths in the hospital, they are the ones we might be interested in.

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Mr STOJCEVSKI - I had an opportunity to talk with three of the coroners ahead of today's committee inquiry. Over my two and half years there, and going back trying to look at 10 years of caseload, we have not had any cases where palliative care has become an issue for the Coroner. That goes to the definition in the legislation of reportable death.

CHAIR - Could you explain that to us?

Mr STOJCEVSKI - Section 4B of the act is relevant here. 'Reportable death means a death where the body of a deceased person is in Tasmania or the death has occurred in Tasmania ...' - that is a jurisdictional issue - '... being a death that appears to have been unexpected, unnatural or violent or to have resulted directly or indirectly from an accident or injury' - the key terms are unexpected and unnatural or violent. In a palliative setting there is not going to be a lot of those deaths reported to the Coroner because they are neither unexpected nor are they unnatural, unless someone has -

Ms OGILVIE - There was some intervention?

Mr STOJCEVSKI - That is right. There is that definitional issue. The other one is the medical setting that occurs during a medical procedure - and note 'medical procedure' because I will come back to that in a moment - or after a medical procedure where the death may be causally related to the procedure and a medical practitioner would not, immediately before the procedure was undertaken, have reasonably expected the death. If the medical practitioner could reasonably have expected the death, then it would not necessarily be reportable.

Going to medical procedure as defined in the act, 'a medical procedure means a procedure performed on a person by or under the general supervision of a medical procedure, and includes imaging, an examination - whether internal or external - and a surgical procedure'. Based on that definition, it does not include the administration of drugs.

Ms OGILVIE - Drug overdose?

Mr STOJCEVSKI - It does but that comes under 'unnatural'.

Ms OGILVIE - That is more a drug use issue as opposed to a palliative care medication scenario?

Mr STOJCEVSKI - That is right. We had a case recently that was publicly reported in the Mersey community where there was a drug overdose which led to violence. If that case was palliative and that woman was suffering a severe form of cancer and the medical practitioner knew that would result in her death, that would not have come to the Coroner. It was because of the nature of the drug overdose that it came to the Coroner's attention and that was reported to the Coroner on that basis.

Ms OGILVIE - We have heard evidence during this hearing at various locations around the issue of palliation and medications used. It is my understanding that there is a form of titrations, a document that the medical profession use above and beyond which it would seem to be outside normal usage for those particular medications. In the case that you have spoken of in particular, where more is given than would be standard practice, in your experience of the Coroners Courts have you had these scenarios before, or was the recent case at the Mersey a one-off? To clarify, we are looking for who has visibility of those issues?

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Mr STOJCEVSKI - I think the Mersey case was particularly stark. I do not have the case in front of me, but my recollection of the case was that something like 24 ml was supposed to be given over the course of the day and 240 ml was given.

Ms OGILVIE - A big mistake.

Mr STOJCEVSKI - A very big mistake. If it was more in the nature of 24 ml but 30 ml was given, again that probably would not have registered with the doctor reporting the death. I think this is a case in point. In a lot of these cases in a medical setting, if the doctor who signs the medical certificate of cause of death provides a medical certificate then that automatically results in it not going into the coronial -

Ms OGILVIE - It closes it out.

Mr STOJCEVSKI - Yes, it doesn't come into the coronial jurisdiction. If the medical practitioner could not reasonably have expected the death, but in a lot of cases in palliation they would in fact expect a death -

Ms OGILVIE - It might be about timing.

Mr STOJCEVSKI - Yes. They will not report the case to the coroner. That comes through the hospital. I know the Royal Hobart Hospital has a Death Review Committee internally, but I am not certain about the other regional hospitals. Certainly that will go through the internal Death Review Committee and then, unless there is a problem at that review stage, they might refer it at that stage to the Coroner's office. Generally, having spoken to three coroners before today and having a look at 10 years of previous cases, there has never been a case where palliation has been put under the spotlight by the Coroner's office.

Ms DAWKINS - The only other way it would come to you would be by the police? If an individual had a concern they would go to the police and it would come to you that way?

Mr STOJCEVSKI - That's right. That might be a family member.

CHAIR - Have you had any examples of that coming to the Coroner's office?

Mr STOJCEVSKI - There is a case presently that is being investigated. I am not certain at what stage that investigation process is at, but that case looks as if it will be a case where it will examine the nature of the palliation involved. Again, that is probably the first case we have had in the past 10 or so years.

Mr JAENSCH - Can you give us an idea of what the steps are in an investigation, hypothetically? What steps do you take? We've been hearing a fair bit about this environment of palliation and there is a lot of judgment, timing and intent tied up in all this stuff. How do you set about making an investigation?

Mr STOJCEVSKI - I will focus on medical deaths in the first instance. In a hospital setting it will usually be the relevant medical practitioner or doctor who reports the death to the Coroner if they think that the death was unexpected, unnatural or violent, such as a massive drug overdose or there was some disease not apparent at the start. Or a surgical procedure done and it did not go

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according to plan and the person died after the surgical procedure. They usually come direct to us from the hospital.

Ms OGILVIE - So effectively self-reporting?

Mr STOJCEVSKI - Yes. Then a coroner's associate, who is a police officer and works in the coroner's office, completes a report of death for the coroner. This is essentially the referral document that gives the preliminary cause of death and sends to the next of kin details - age, gender, job, what happened beforehand and how they got to hospital. That is provided to the coroner and then an investigation proceeds.

In a medical setting that investigation typically involves collecting affidavits from a medical practitioner, the nurse or other relevant people in the hospital setting. That will also involve collection of all the hospital medical records. Seizure of the hospital medical records to see what precipitated that person's admission to hospital and what happened during that person's stay in hospital. All that becomes part of the coronial case investigation file.

We have a procedure in Tasmania where we have Coroner Rod Chandler who does probably 80 to 90 per cent of medical adverse deaths. Coroner Chandler has set up a procedure that involves a retired medical practitioner who is an intensive and emergency medical practitioner on our staff. His name is Dr Tony Beale. He looks at the file. We have a clinical nurse specialist who again looks at the file, in typically a working group-type scenario, and they then collect the evidence. They will look at goals of care, medication, how that person's stay was in hospital, any factors of interest, such as pre-hospital admissions, or admissions for similar diseases in the past. So they will slowly go through -

Mr JAENSCH - Are you able to take account of things like an advanced care directive, if it exists?

Mr STOJCEVSKI - An advanced care directive of goals of care document would typically be looked at by our clinical nurse specialist. She will look at what was in place. She will compile that and then there might be a bit of to-and-fro between the medical practitioner and the hospital - 'Can you tell me why pathology wasn't staffed at that time?' or 'Why was the consultant off for five days?', 'Why didn't you contact the consultant on those days?'. A fair bit of to-and-fro, especially if the coroner thinks there is a potential lapse of judgment. They will do it in a very active way and they will go to the hospital and ask questions of the hospital that may not be apparent. Prior to the final findings and recommendations being released, we will typically engage the medical practitioner or the hospital through their executive director of patient services with the nature of the recommendations and we will give them an opportunity to provide a final statement or comment, especially if they are potentially adverse findings against the medical practitioner or the hospital.

Ms OGILVIE - Is there a conversation that happens with the family at that stage, or is this purely information gathering?

Mr STOJCEVSKI - Conversations happen with family. Conversations would happen with the family early, have them through the coroners associate. One of the chief functions of the coroner's associate is to take some of those statements and affidavits from a family.

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We had a case recently where a person in hospital died as a result of a twisted lower bowel. The person went to the hospital with his wife, so a statement was taken from the wife. We will typically engage a family early on and then throughout, especially if the family is having trouble understanding the nature, and we will engage the family afterwards as well.

Once we release the findings, which goes to the family if we publish those findings, we will often, as findings in a medical setting can be quite obtuse to family members, have Tony sit down with family members after that and take them through and say what it is.

Ms OGILVIE - To explain it?

Mr STOJCEVSKI - Yes, that is right. He is a fantastic resource in that regard.

CHAIR - We have heard evidence in two aspects. In considering the issue of palliative care and how to improve palliative care we have heard evidence that implies some people are not being able to die early enough as palliative issues and have also heard some evidence some people are dying earlier than they should, perhaps.

In your view, in terms of the Coroner's Office, how do we guide to ensure we are getting the highest quality of care for Tasmanian patients that navigates through the pathway between not soon enough within the palliative context?

Mr STOJCEVSKI - It is a very difficult question. What I said at the outset is we do not get a lot of palliative care cases in the coronial jurisdiction. The Alzheimer's cases, the long-term dementia cases, typically will not come to us because there is a natural death in those situations. Whether they are palliated or not and the degree to which they are palliated, if there is a medical certificate signed by a doctor at the end of a death, where death was expected, that will not come to us.

The questions for the Coroner are, in a broader sense, and we went through a presentation on this in 2014 at the Asia-Pacific Coroners Society Conference which was held in Melbourne by medical practitioner, Dr Charlie Corke. He spoke to us about providing people with enough material to have conversations. I noticed Professor Michael Ashby provided a statement about conversations and engaging early.

Often in the coronial jurisdiction, those conversations will not have occurred because it is sudden expected. If a person has a very serious car crash, they are not in a position then, and if they have not written down a goals of care plan or a value statement about what they would like and then put it in to a state of extended life support, they are not in a position to have an advanced care directive or a goals of care statement.

That is the issue in terms how then can a coroner determine that person. He becomes a coronial case because of a violent and sudden death. But the question for the coroner is, did the person have enough documentation in the medical setting to provide the coroner with appropriate checks and balances for the medical practice. It is arguable whether that is the case at the moment.

CHAIR - Which body is appropriate to review end of life care? It is too soon? Is it too long? Where does that review occur? These deaths in palliative care are expected, usually non-violent and they are not going to come into your jurisdiction?

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Mr STOJCEVSKI - I do not know. It is not an area I have researched and turned my mind to. I cannot provide any assistance on that.

Mr JAENSCH - Take the situation in which a family might speak to police about a patient in a palliative care setting - at home, a nursing home, or in hospital - raising questions about whether their death had been unduly hastened. We listen to different perspectives on this, and we understand there is the somewhat grey area of intent. The difference is between administering medications to relieve suffering, but which may have the additional effect of hastening death, but the principal intent has seen it as a last resort in pain management - in administering something which may render someone unconscious. This is opposed to rendering that dose, or slightly larger, with the intent of bringing on that person's death. Is this a matter the Coroner might examine to determine intent, and what the evidence reasonably points to as being the judgment of a practitioner in that situation?

Mr STOJCEVSKI - I note the relevant section of the Criminal Code is a bit grey about this area. On a self-reporting or police reporting basis, if a family member thinks a medical practitioner did something untoward in hastening a person's death, then we will advise that person they should report it to the police.

CHAIR - So it goes around in a circle?

Mr STOJCEVSKI - Yes. We will advise them to report it to the police. We can put that person in contact with the police. Our coroner's associates are police officers. If there is something unduly unusual about that case, that will be investigated in the normal manner as a police matter. It might then be seen as a case in the coronial jurisdiction if certain elements, consistent with the legislation, are met. If the statements of the family, the doctor and some other people are, 'We knew your father was really sick and we knew he was eventually going to die, we said it was going to take three to six months, so we made him suffer less in that process but we knew he was going to die', according to the legislation that will not become a case for us.

Ms OGILVIE - You have spoken a bit about the process of reporting. I am interested in deaths in hospital, where we have greatest visibility of the process. There is a Mortality and Morbidity Review Committee within the hospital. Do you have interaction with that?

Mr STOJCEVSKI - We haven't in the past, but we are meeting with them next week to discuss better linkages. To say we haven't is not entirely correct, there have been linkages, but they have been fairly informal and ad hoc, and there has been some confusion about how those linkages are to occur. We are trying to streamline those. We are of the view that rather than having an ad hoc linkage with this committee, if they think there is a matter that merits review by the Coroner, they should do that by submitting a report of death.

Ms OGILVIE - They should be in conversation with you?

Mr STOJCEVSKI - Yes.

Ms OGILVIE - That committee has appointed a number of medical practitioners. There is also a lawyer, and the people on that committee would change from time to time. I believe it reviews all deaths within the hospital setting?

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Mr STOJCEVSKI - That is my understanding. All deaths where a medical certificate of cause of death is done in the hospital setting goes to that committee.

Ms OGILVIE - So, review goes on within the hospital around those issues. Would you think it might be a good thing that the Coroner has some form of representation on that committee, or are you thinking of a more connected process between the two organisations?

Mr STOJCEVSKI - I think it would be very, very problematic if the Coroner was to have representation on that.

Ms OGILVIE - It might scare everyone?

Mr STOJCEVSKI - If it's made up of doctors -

Ms OGILVIE - It is an internal review.

Mr STOJCEVSKI - That's right, yes. I think it would be very problematic to have an independent judicial officer, who has a review mechanism on all those doctors, to sit with those doctors.

Ms OGILVIE - The preferred mechanism might look like?

Mr STOJCEVSKI - We are going to start that conversation next week. There were ad hoc and haphazard relationships. A particular doctor with particular concerns might have come -

Ms OGILVIE - They would know who to speak to, I am sure.

Mr STOJCEVSKI - That's right. They would try to speak to the Coroner's Associate, but we have to try to streamline that process, so it becomes a lot more transparent than it currently is.

Ms DAWKINS - A general question, we have heard a lot about the potential improvements to death literacy throughout the community in Tasmania. This inquiry is a part of that. Do you think the Coroner's Office would have a role in improving death literacy in Tasmania?

Mr STOJCEVSKI - Definitely. We embarked on a project last year where we managed to gain some funding from the Law Foundation of Tasmania to produce a coronial practice handbook, which is due for release in late October. I have been with the Coronial Division for two-and-a-half years and I was concerned, and ultimately motivated, to provide this coronial practice handbook. It is for lawyers, which is the first audience that we are trying to engage, because the nature of inquisitorial judicial process is quite alien to lawyers who have been educated in an adversarial process.

Ms OGILVIE - A more combative style.

Mr STOJCEVSKI - Yes. Where the Coroner guides the investigation, it does not work well with the typical training of a lawyer.

Ms OGILVIE - With the training, let's be blunt.

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Mr STOJCEVSKI - Yes. We are producing a coronial practice handbook, but we are also - as part of that handbook - producing a document for friends and family. This will go into things like objection to autopsy, organ donation, what happens typically in the first 24 hours after a coronial death, issues related to how friends and family might make application to the coroner to appeal a death. That is set out in the legislation, but people can be quite alienated from it.

We are in the late stages of developing a coronial practice handbook and we hope to see that distributed to lawyers and more generally to LINC's and community -

Ms OGILVIE - To work with the hospice people?

Mr STOJCEVSKI - Yes - local government, funeral directors and so forth to give them a better sense of what is involved in coronial practice in Tasmania.

CHAIR - Do you think it would be appropriate that the committee obtain a copy of that document from you?

Mr STOJCEVSKI - Yes, I would be happy to.

CHAIR - In regard to the mortality and morbidity review committee, that is not a THO statewide thing but is hospital by hospital?

Mr STOJCEVSKI - That is my understanding - hospital by hospital. Next Monday we are meeting the RHH committee. Most of the hospital deaths occur in Hobart in the south; we have not been approached by other hospitals. Our meeting was based on an approach from the RHH committee. They approached us to have a discussion about some of their procedures.

CHAIR - I would like to slightly change the subject. We have had lots of evidence that many people's preferred place of dying is at home and that a lot has been done to enable people to die at home. What procedures, oversight or review would you consider appropriate in that environment where it is much less regulated, peer reviewed, et cetera, to ensure practices are appropriate?

Mr STOJCEVSKI - It is a very difficult question. I am not qualified to provide comment on that. It is very difficult where we haven't had specific coronial findings around palliative care or palliative care cases in jurisdictions that enable me to make comments about that area, which is not an area I have any qualification in or have done any research on.

CHAIR - In saying there have been no palliative care cases, does that imply there is no need? I am only asking your opinion, but is there no need, or people just don't understand enough to know how to get into the coronial system if they have concerns?

Mr STOJCEVSKI - About the need, I think that is a matter for the Government and the legislature. About connecting more people with the coronial jurisdiction, that is something we are trying to do, trying to educate more people about the coronial jurisdiction. Over the last 12 to 18 months we have tried to have stronger linkages with a number of stakeholders in that area, and I think the Law Foundation is one of those. I think we have good linkages with Police and Emergency Services. I think we have good linkages with the DPP's office, but it is an ongoing issue for us to educate the general community about the nature of coronial practice.

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We have a very good relationship with the state Forensic Pathologist, for example. He sits on our quarterly meetings - we meet each quarter with the coroners - and we have a very strong relationship with him. He told me the other day that medical students whom he lectured to thought that he was the Coroner. There is a bit of work to do. Everyone does not necessarily understand that the Coroner is a judicial officer and the powers the Coroner has.

All our findings are guided by this statement in section 28 of the Coroners Act: 'A coroner investigating a death must find, if possible, the identity of the deceased'. Often that is not a very contentious issue. 'How death occurred' - the cause of death. The cause of death might be blunt traumatic injuries to the brain as a result of a car accident. In the context of 'natural', it might be cardiac arrest. 'When and where death occurred'; typically that is not going to be a very difficult issue. 'The particulars needed to the register the death for the purposes of the Births, Deaths and Marriages Registration Act.' Those five elements are the functions a coroner has. Over and above that, section 28(2), 'A coroner must, wherever appropriate, make recommendations with respect to always preventing further deaths and on any other matter that the Coroner considers appropriate'. Section 28(2) is read in the context of section 28(1). It is not investigation at large.

CHAIR - It is specific?

Mr STOJCEVSKI - Yes. It is guided by those issues about how the death occurred, the cause of death, when and where death occurred.

CHAIR - Thank you, that was really insightful and very helpful to us.

Mr STOJCEVSKI - I will be happy to direct a copy of the handbook to you. The handbook will be entirely web-enabled. It will be fully searchable on the web. That means if you look for 'reportable death' on the web version it can take you straight there.

THE WITNESS WITHDREW.

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Ms PIP LEEDHAM, DIRECTOR, COMMUNITY PLANNING AND STRATEGY, **Ms CHERYL GARRETT**, GENERAL MANAGER GOVERNMENT RELATIONS, POLICY AND PROJECTS, AND **Ms ANITA REIMANN**, PROJECT MANAGER, BETTER ACCESS TO PALLIATIVE CARE IN TASMANIA, DEPARTMENT OF HEALTH AND HUMAN SERVICES, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR (Ms Rylah) - Welcome. This hearing is a proceeding of Parliament. That means it receives the protection of parliamentary privilege, an important legal protection that allows individuals giving evidence to a parliamentary committee to speak with complete freedom. This protection does not apply outside this hearing. This is a public hearing, but should you wish evidence to be heard in camera you must make this request and explain why prior to giving that evidence.

Ms LEEDHAM - I am acting as the deputy secretary, planning, purchasing and performance for the department, and I am here as the secretary's nominee.

I thought it was useful to bring Anita Reimann. Anita is the project manager for Better Access to Palliative Care in Tasmania, which is the project we have been leading for the last three years with funding from the Australian Government. I also have Cheryl Garrett, the Acting Manager, Government Relations and Strategic Policy. We have been working as a trio for the last three years, in relation to palliative care.

Thank you for inviting us. It is something of interest to everybody and a passion for all of us in how we are working with the service system.

Whilst the department led the whole-of-government submission, we had input from Justice, DPAC and from the Health Service, today we can be here to talk from the department's perspective in the department's role of system manager.

I have already communicated that to the committee via email. It was important to put that in context. If you want stuff specifically related to the specialist palliative care services, you would need to have a conversation with the Health Service in relation to that.

You are right with what you have said. There is greater recognition and understanding about palliative care and the fact it is delivered in all health and community care settings. It is right across the board. It is in the primary area, the community area, and there is a significant proportion in the age care sector as well. There is recognition of the need for palliative care in the disability sector now as well.

It is an interesting evolution. When we talk about contemporary approaches to palliative care, you will hear terminology, such as creating a circle of support that is delivered by communities of care. That surrounds the person who is dying, their family, their extended family network, and it is around maximising their quality of life and wellbeing at end of life.

When we talk about community as a care, we are talking about hospitals, health and community care providers, volunteers, social networks, clubs and neighbourhoods, local organisations, faith groups, business groups and people living in a particular area. It is like this

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huge support network. This is a better one to explain that - if I can table that, you can see the person at the centre of it.

Communities of care is provide practical support and care for those who are dying, those who are experiencing loss and also for those who are bereaved. That is the broader concept.

The department purchases palliative care services from the Tasmanian Health Service, through the service agreement. Those services are an integral component of what the THS delivers. That includes community nursing, allied health, specialist palliative care services, acute care, the hospice and the services provided in all rural health facilities.

It is interesting you talk about people's interest. It is happening at both a national and a state level, as considerable service and policy development has gone on. Contemporary approaches to palliative care are much more oriented around the whole of community, inclusive approach, which focuses on health promotion, prevention, harm reduction and community participation.

However, that approach is not widely understood or embedded in practise. That is where the work is occurring now, to embed it into practice. To do that requires partnerships between palliative care services and the primary care practitioners, in particular GPs, and the development of strong links with community groups and services.

Policy making in relation to palliative care and end of life is occurring nationally. Work is underway. The Commission of Safety Quality Health Care has produced a National Consensus Statement: the essential elements for safe and high quality end of life care. I do not know if you have seen that document yet?

CHAIR - Could you provide us with a link to that then?

Ms OGILVIE - What was that again?

Ms LEEDHAM - It's called the National Consensus Statement: essential elements for safe and high quality end of life care. It spells out what is required across all health services. It is a fantastic piece of work. That is also starting to influence how health services are accredited, because the commission led it. That has linked into some of their consumer-centred standards.

CHAIR - When was that document released?

Ms LEEDHAM - Last year.

CHAIR - It's quite contemporary.

Ms LEEDHAM - Very contemporary. It was widely consulted. They released draft versions before they released the final version.

Palliative Care Australia is the national peak body. They develop position papers, service development and planning documents to guide governments at all levels in developing evidence-based quality palliative care service systems. That is aligned to the Australian Government's National Palliative Care Strategy released in 2010. The Australian Government is currently looking at its National Palliative Care Strategy to contemporise it.

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If you look at what occurred with the development of the strategy in 2010 and what is occurring now, the scope of palliative care has widened to include life-limiting illnesses. It is also referenced not only to specialist palliative care service providers, it is also very much linked to primary care providers in the whole gamut of settings.

CHAIR - Life limiting illness even in early life?

Ms LEEDHAM - Yes. I think that has been one of the challenges. There is a perception that palliative care is just end of life.

Ms OGILVIE - Just older people as well, it seems to be a theme.

Ms LEEDHAM - If you think about the history of palliative care, it came out of the cancers. If you reflect on the work that the Tasmanian Government did to develop the Palliative Care Policy Framework in 2004, it was recognised then the bulk of clients who were accessing services were the cancers. But there was this growing need with the life limiting chronic illnesses. There is a need for appropriate palliation of those people as they progress through their illness trajectory. If you are talking about appropriate system management for people with life limiting illnesses, then a palliative approach is better early in the piece. One of the most difficult things that can happen is only providing palliative care in the last week of life. If you think about the WHO definition of palliative care, it is about providing support pre-end of life and post-end of life.

Ms DAWKINS - Do you think there is a role for the department to even go one step back and talk to people who are not even ill yet? They might be looking at someone from cradle to grave, and what could happen to them if they were to get a life-limiting illness and have that conversation already embedded in their family and the community.

Ms LEEDHAM - There has been a lot of work done. I do not know whether you have come across Respecting Patient Choices?

Ms DAWKINS - Yes.

Ms LEEDHAM - That was about being able to have conversations with people who had been diagnosed with a chronic illness on how they could start to think about their advance care planning. What do they want? How do they wish to be managed? What are some of the decisions they would like to make that are respectful of their choices?

CHAIR - Before we go into too many questions, I would like you to finish your introduction.

Ms LEEDHAM - Where I got to was the change in focus. The challenge with this change is the need to build greater community awareness, which is what you are talking about, Andrea, and understanding palliative care is not for the last few weeks of life. That is really terminal care.

Ms DAWKINS - Change some of the language.

Ms LEEDHAM - In our submission we talked about all the interchangeable definitions and the confusion that creates.

In our submission we included the Government's approach to the palliative policy settings, service design and delivery, and system roles and responsibilities. The submission also addressed

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the specific terms of reference set by the committee and we provided factual information on current Government policy and practice. It briefly described future work to embed the national standards with best practice approaches for palliative care, how we have planned to improve bereavement care and to deliver the specialist palliative care service models. We are appearing here as the system manager, and we are responsible for managing policy, planning and performance. They are the three 'p's of my title, so to speak.

As the system manager, we support Government to set the overarching direction for the palliative care service delivery in Tasmania and manage the interface with the national palliative care policy in practice frameworks.

Historically, the approach has disproportionately focused on the acute care setting and specialist services. Currently we estimate over 70 per cent of palliative care is delivered in the community by primary care providers. Therefore, it is really important we note the extensive role the primary, community and age care sector plays in this particular arena. That is where the thinking was when we were offered that money through the health assistance package for the Better Access to Palliative Care Program, to develop a more contemporary strategic direction for palliative care and the focus in the community space.

We have done a heap of work. Anita has led a very capable team for this process. We have focused on collaboration, networking and have built system capacity. We have strategies in place to build capacity and capability of the communities of care you talked about. We have developed the Tasmanian Palliative Care Service Formulary, which will be an online resource for health care professionals in caring and prescribing for patients receiving palliative care. We have it up on the DHHS intranet now and we are just going through a range of IT challenges to actually be on the internet. Any primary care provider actually managing someone in a palliative approach and needs advice in relation to treatment for medicines or alternative medicines, that is all there and will be available. This has had significant input from primary care providers in the development.

We are in the process of finalising a palliative care community charter, which is really is the community's way of saying what they want from this area. We have also developed some sector-wide driven end-of-life care projects which have built on the work the Tasmanian Health Service did on advance care planning and their Medical Goals of Care Plan. We have worked extensively with Primary Health Tasmania with their health pathways. I do not know whether you are aware of that. This is an internet-based system for health professionals and particularly directed at general practice. If they are managing someone who is palliative, they can get into a pathway, look up palliative care and can find how to best manage the person if they need to refer. All of the referral options are there. It has been a significant piece of work done by Primary Health Tasmania. You can look at the website. It is called <http://tasmania.healthpathways.org.au>. You have to be a health professional to actually get into the detail, but it will show you the framework. There are pathways on everything; every particular illness you could ever imagine. There are about 450 live now.

Ms OGILVIE - This is on the pharmaceutical?

Ms LEEDHAM - No, this is general. A GP managing an adult with cardiac problems can look at the cardiac health pathway website and it will take you through a whole lot of things. If it is getting to the stage where a palliative approach is needed, there will be a link then to take you through to the palliative process.

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It is a fabulous piece. The really good thing about it is the referral pathways. For International Medical Graduates providing general practice in rural areas, it is an invaluable resource because it gives them directions as to where to refer them.

Ms OGILVIE - Local knowledge.

Ms LEEDHAM - Yes, it is localised. That has been very exciting. Then we are developing a palliative care policy framework which will again focus on this more inclusive and contemporary approach to palliative care. Shifting to the community approach and recognising all the settings where palliative care is provided and recognise this circle of support.

They are common themes and the communities of care that naturally surround the person who requires palliative care. It will outline the strategic directions for palliative care in Tasmania and establish priority areas for action to ensure there is continued improvement for palliative care.

It also supports the government's health service reforms, continues the reforms and initiatives delivered through Better Access to Palliative Care and will embed national standards and best practice. We anticipate the framework will be released towards the end of this year.

Mr JAENSCH - A clarification first and a question. Thank you very much all for coming in and for your submission.

You were referring to 'life limiting illness' before and you have used also the term 'chronic illness'. There are chronic illnesses which limit quality of life but not so much duration. When you talk about life limiting illness, do you mean things that are going to bring you to an earlier death?

Ms LEEDHAM - Any chronic illness impacts on people's quality of life. They actually have to make some decisions about how they manage their chronic illness.

Mr JAENSCH - Diabetes?

Ms LEEDHAM - Diabetes, asthma. Some of them have a much longer trajectory and a deterioration path, whereas some of the others, when you think of a motor neurone disease, they have a much shorter trajectory. It is about how you provide care appropriately and support those people to live as independently as they can for as long as they can. When you think about it, most of their life is actually outside of the health sector.

Mr JAENSCH - In the context of this inquiry and palliative care, and you are encouraging us to think about palliative care not just as the terminal care but as the care over the life of an illness or of a life. There is a difference between managing a chronic condition, and should we routinely be referring people with diabetes to places that offer palliative care? Where do you draw the line?

Ms LEEDHAM - I do not think you can say that there is a clearly defined point where you refer.

Mr JAENSCH - When do we call it palliative care?

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Ms LEEDHAM - We talk about care in a palliative approach. Let's go back to Andrea's earlier question. One of the things you would want to encourage is for people with chronic illnesses to start to think about the advanced care plan. They could start to think about what it is and how they wish to manage it.

Mr JAENSCH - Because of the likelihood of complications, et cetera, and higher risk of certain things?

Ms LEEDHAM - Anita has been much more engaged in consultation in relation to that. I do not think you can say, at this point in an illness, that is when you refer them to palliative care. It could be that care is provided in a palliative approach, and part of their ongoing discussions with their general practitioner. Their general practitioner has probably asked them to think through things, and how they would better manage themselves in coping with their illness.

Ms REIMANN - There would often be increasing co-morbidity occurring for the individual. When those co-morbidities become more complex, that is when we need to start talking about having conversations about what kinds of care people would like to receive, and what kinds of care they do not want to receive. Some of the challenges around that are people's lack of understanding about particular procedures, what they mean, and what they might look like.

For example, my own strong view is I would not ever want to have a peg feed. Some people with an anxiety disorder do not want to have a mask or anything placed over their face. So, it is being really clear about what is comfortable, what is not comfortable, and what fits with people's personal values. It is difficult to give you a particular point, but usually the complexity of the co-morbidities becomes the real decider, about when it looks like we are going to see a more significant deterioration.

We talk about the surprise question, which is asking would we be surprised if the person died in the next 12 months. It is really hard to give you a particular time frame for palliative care. The learnings from Better Access to Palliative Care - BAPC - are that we need to start earlier. We need to shift people's focus from it being the last two weeks of life, or the last three weeks of life. That is what we call terminal care. It really is about starting that planning and that discussion much earlier.

Mr JAENSCH - In relation to that, of the Tasmanians who have a diagnosis or a set of conditions that might be best managed, treated and planned for through a palliative approach - how am I doing? - what proportion of Tasmanians get that planning?

Ms LEEDHAM - The challenge is that not everybody needs access to specialist palliative care services. We think that only 30 per cent of the people who require a palliative approach need access to specialist palliative care services.

CHAIR - Is that comparative nationally?

Ms LEEDHAM - That is part of what the data is saying. Everybody needs to have a productive relationship with their primary care providers. That needs to be the conversation between the person and their primary care providers.

Mr JAENSCH - I am picturing some people I have met who are old, unwell, and alone in a house with a cat and with the curtains drawn. I meet people like this. I am sure they would

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benefit from having more care around them. When we talk about better access to, better than what? What is good? What are our numbers, and how are we going? What are we aiming for in providing palliative care?

Ms LEEDHAM - You have to look at the circumstances. You are talking about those older people that are living at home. There is a change going on in the aged care sector. One of the things being developed nationally is My Aged Care, which is a website and a phone line. Advocates, or providers, for older people can call that phone number on behalf of the older person, or the older person can call themselves. That would link them into service or provide them with information about service available in their own community. For an older person like you are describing, one of their first reference points would be to contact My Aged Care.

Mr JAENSCH - If we are not working on a metric with this because there are so many different pathways into it, how are we going with, for example, GPs - adequately or early enough - identifying the need for access to complex care planning with people who have life limiting illness? Or are we still seeing a default to treating what is presenting, today?

Ms LEEDHAM - No. There has been a whole lot of work. In the submission we referred to the advanced care planning and to the Medical Goals of Care Plan. Medical Goals of Care is a document developed by the treating doctor. It has been developed in the hospital environment to make some decisions in conjunction with the patient, or the patient's family, around whether the goals of care are curative.

Mr JAENSCH - How many people who have had a life limiting illness leading to death die without an advanced care plan?

Ms LEEDHAM - I do not think we can tell you the numbers at this time. The data is not clear. Considerable progress has been made over the last three years. Significant funding has been put into resourcing and supporting general practice and the broader service system in relation to how to provide care in a palliative approach and how to support them to have these conversations. Whilst Goals of Care Plans were originally developed for the hospital environment, it is now being rolled out within the general practice community. The Goals of Care are one of the links on the -

CHAIR - We haven't heard about that before. We may have heard about it in the hospital context.

Ms LEEDHAM - The Goals of Care are now on health pathways.

Ms REIMANN - Yes.

Ms LEEDHAM - If a GP was actively engaged and wanting to, that can link straight into the HealthPathways website and get the Goals of Care form. We have also done some work with Ambulance Tasmania, so that if Goals of Care are available, they will recognise it in the transfer of patients between settings.

Ms REIMANN - In terms of the Goals of Care, the work we are focusing on at the moment is building capacity in the primary care setting. When a Goals of Care comes out of hospital setting the GP know what it is, they understand how it informs their care. At transition points,

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with people coming into hospital for planned procedures, the GP is able to update the Goals of Care and the person comes in with an updated Goals of Care.

This morning I have signed off on some further funding with Primary Health Tasmania, as well as with Palliative Care Tasmania, to provide that training. We will not only be focusing on GPs because they are busy people, we will be talking to practice nurses and practice managers to support and promote the use of Medical Goals of Care. Coupled with that, promoting the use of advanced care directives and the advanced care planning process.

In terms of your question about better access, it is not such a case about increasing the amount of advanced care directives. It is about building skills and comfort within the community. It is also about building skills within the service provider sector to have conversations about death and dying. People have to be in the right space to have that conversation, and to raise that issue in a way people are not going to walk away thinking, oh my goodness, I could die tomorrow. That is a normal, comfortable part of having a conversation and planning for your care. That takes a lot of skill in training and sensitivity and responding to emotions. It is a significant skill and people have their own values and feelings about how comfortable they feel with having that conversation.

As a health professional, even though it might be part of your role, you still have your own thoughts and feelings about how you proceed with the process. That is the kind of work we are doing in building that level of comfort, but also helping people to understand from the community perspective. It is no good us doing a whole lot of good work in the health system if the community is not prepared to engage in the conversation. That is where palliative care in Tasmania has done work in raising people's comfort and ability to have a conversation about death and dying. Even if they do not fill in an advanced care directive, at least having the family know what their wishes are so they can inform the health provider who often is trying to make decisions about the care.

Ms OGILVIE - I want to tackle a slightly different part of the conversation, and it is something close to home for me, parents caring for a dying child. When we talk about respecting patient choices, the parent who is standing in place of the child, what sort of work have you done around this issue and what work is there yet to do, do you think?

Ms LEEDHAM - I am just thinking it was picked up in a piece of work that was done around the Northern Hospice Feasibility Study. It was particularly a term of reference we asked the consultants to look at. Of course Anita managed that.

Ms REIMANN - Most of the palliative care needs for young people are quite complex. It is a family-centred approach in terms of the provision of care. It often requires a larger network. My observation and certainly the feedback I have heard from consumers on the ground is they prefer to have stronger connections with a small group of people from the beginning right through to the end. That needs to continue after the young person dies, because those networks have often been there for a number of years. Because it is such a specialist area and we often do not have the numbers - I do not mean to be disrespectful - but the numbers we get with adult presentations, developing those particular skills is quite a unique thing to do.

We are using a lot of support from Victoria. Recently we brought out some specialists to provide some workshops and training in the palliative approach for young people, paediatric

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palliative care for our specialist teams and also working with our paediatric services in the state to try to build some of that capacity.

Ms OGILVIE - To shrink it down even more to an even smaller component in the neonatal setting. What work have you done or should be done in the neonatal setting around palliative care?

Ms REIMANN - I cannot give you any feedback on that.

Ms LEEDHAM - Unless the neonatal setting was encouraged to participate in that training.

Ms REIMANN - Which they were.

Ms OGILVIE - We do not know, or they have not?

Ms REIMANN - It is a very direct clinical question for the THS, which is outside what I can comment on.

Ms LEEDHAM - We recognise it is a specialised area and an area where capability needs to be built. But recognising the circumstances associated with it, we have used some of the resources available to us to build that capability.

Ms OGILVIE - My personal view is it should be coming from them not so much as suggesting you need to do more. I was just trying to find out how much engagement there had been.

Ms LEEDHAM - It is a part of building capability and it is about having the generic conversation about the communities of care and circle of support. As you build those conversations people start to think a little bit more broadly as to how it can be put into practice.

Ms OGILVIE - And some training too.

Ms DAWKINS - I have a question about the Healthy Pathways, the on-line forum?

Ms LEEDHAM - Health Pathways.

Ms DAWKINS - How many GPs are using it? Can you give me an idea of percentages? Is it growing quickly?

Ms LEEDHAM - It is growing.

Ms DAWKINS - Is there a bigger doctor rate?

Ms LEEDHAM - The last lot of metrics I saw were in June or July. It is growing and it grows each month as it becomes more apparent. GPs will go in and out of the system depending on what they need in relation to a consult that they have going. It is a desktop icon on their computer. If you have been to your GP lately they do play with their computer regularly, don't they, and they will print out information for you in managing. That can often all be linked to Health Pathways. The repeat use percentage of people once they have used it for the first time is about 70 per cent or 80 per cent. It is growing as people become more used to it, and GPs have

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been involved in the development of the localisation of the pathway. Primary Health Tasmania has brought groups together which have the specialists and primary care providers to have a conversation about how those pathways and referral mechanisms are to be used. It has been rolled out by a whole lot of primary health networks across the country. The difference for Tasmania is a whole-of-state approach. If you get into a pathway you will see three different referral strategies depending where you live and what the particular illness is.

For some things there will only be one referral pathway, but for others they will be more localised as to what to do in your local area.

Ms DAWKINS - Would there be a time in the future where you would be looking at 100 per cent? For example, someone over the age of 70 visiting their GP, would you expect at some point, their GP would be looking at that tool with them?

Ms LEEDHAM - Again it would depend on why they presented to their GP, what the GPs special interests are. The utilisation of them across the country, and in New Zealand where the whole idea first started, is it has made a huge difference to general practice and has actually improved the quality of care. It has improved the mechanism by which GPs get information, when there has been changes in practice standards or something like that.

Canterbury, where it all started, use this beautiful example to do with paediatrics around the medication procedure. A noted paediatrician had talked about what was supposed to be occurring. When they did some research, the evidence was less than desirable. They were able to change the whole pathway in relation to what was now contemporary practice. It changed the GPs' management of paediatric cases for whatever the particular instance was in 80 per cent of the cases. In the past they would have put an information sheet onto the fax and sent it to a general practice. You know how busy GPs are - it is the luck of the draw as to whether the practice nurse or manager would actually pick up the fax and communicate it to the GP. This is a much more effective and safer way.

Also, built into the pathway is an alert system so if a GP wants to question anything, they can ask the question. It goes back to the pathway's source and it is amended. If there has been a change in practice or medication, an alert comes back to everybody, please note this pathway has been amended for these particular reasons. The pathways are reviewed every two or three years or earlier if there has been some change.

It is one of those really good news stories actually making a huge difference to practice.

CHAIR - We have had a lot of very positive comments about better access to palliative care but we are also aware federal funding is about to come to an end. We have also heard some really good comments about Palliative Care Tasmania in terms of the work they are doing collaboratively in regard to that. Can you give the committee some idea on when the funding decision is or where it goes? Is this going to become a state responsibility? Give some idea of where it is at.

Ms LEEDHAM - There are two things I will say. There is an evaluation underway, of the Better Access to Palliative Care Program commissioned by the Australian government. The evaluators are due to report in the next couple of months to the Australian government. Hopefully the report will be made public. The Australian government will consider the findings of the report and make their decisions accordingly. We are keen to see the report to make some decisions.

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There has been some rollovers. Some of the programs have been continued for a period of time because they did not expend all of the funds within the time available. The funding actually ceased on 30 June this year. We have rolled over some of our funding to continue to do some system and service development.

The district nurses have been able to rollover their funding and continue to provide the hospice@Home packages. They will not take any new referrals from March next year. Palliative Care Tasmania which was another funded party. Their funding ceases in September - this month.

CHAIR - Do you think that may become a state responsibility?

Ms LEEDHAM - It is too early to say.

It has been good to share with you what is occurring because it is very interesting. It is with great pride that we acknowledge a whole lot of the work that has been done to date.

CHAIR - That is absolutely the sense I received in hearing your evidence today. It is amazing to see and hear what you are doing in that area and we can see a great need for that. It is wonderful to hear we are doing it in this state. Thank you very much.

THE WITNESSES WITHDREW.

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Ms DONNA SPONG, REGISTRAR, GUARDIANSHIP AND ADMINISTRATION BOARD WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Ms Rylah) - This committee hearing is a proceeding in Parliament. This means that 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 of place out of Parliament. It applies to ensure that the Parliament receives the very best information when conducting its inquiries. It is important to be aware that this protection is not afforded to you if statements that may be 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 that, should you wish all or part of your evidence to be heard in private, you must make this request and give an explanation prior to the giving of that evidence.

Ms SPONG - I have been 18 months as registrar, so I don't have vast experience. Unfortunately our investigator who has the legal experience is away today. She is also on the Mental Health Tribunal board. The new president commenced on 1 August - Rowena Holder; she is also at the Mental Health Tribunal. It has a training day today in Campbell Town.

CHAIR - Is there anything you would like to tell us about the role of the Guardianship and Administration Board as background?

Ms SPONG - Not really, because, although it is a small act, it is very involved. It depends on what the specific questions are because it is just so broad.

Ms OGILVIE - We've been doing a lot of listening around palliative care, end-of-life decision-making and those sorts of things. I have a particular interest in end-of-life planning and advanced care directives. In one of the depositions we heard about elder financial abuse, when somebody gets a power of attorney and then were able to do not the right things, and the involvement of the Guardianship Board in making determinations around those issues. Could you flesh out what that process looks like, or a circumstance in which these issues have come up?

Ms SPONG - There are many circumstances.

Ms OGILVIE - I understood it is not unusual.

Ms SPONG - Are you talking about when a power of attorney has already been registered?

Ms OGILVIE - Yes, say somebody who has dementia and there is a power of attorney with one person; how does that work if there is an issue reported to the board?

Ms SPONG - The board needs to receive an application to review an enduring power of attorney. There has to be an enduring power of attorney because there are many old ones and there are many powers of attorney that are not registered.

Ms OGILVIE - It must be registered under your act?

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Ms SPONG - No, under the Powers of Attorney Act. The recorder of titles registers powers of attorney. We do not register them. We only have the power to review.

If any party, any person, sees it - a neighbour, a friend in hospital - any person can make an application to review that power. The board receives the application and notifies the attorney if it is not the attorney applying. Sometimes the attorney applies and sometimes it is another family member or a neighbour; it could be anyone. They apply and the board has to notify the attorney or the attorneys that are named in the power. Then it investigates what evidence there is, whether it is frivolous or whether there is some substance to the application. Then it gets listed for hearing. Then it follows the same as the Guardianship Act hearing.

Ms OGILVIE - Would that hearing be the full board?

Ms SPONG - When you say 'full board', the board can sit as one member, but the new president has brought in that at least two legal members do reviews of enduring power of attorney. They are often complicated.

Ms OGILVIE - Yes. Is it your understanding or experience that the issues around the financial side of end of life, precipitate a lot of these issues? Is it a regular occurrence that there would be family coming complaining of bad behaviour on the part of somebody who has one of these powers of attorney?

Ms SPONG - I would not say it is at the end-of-life stage. It could be that family members often think everything is going fine and then all of a sudden someone will say, 'But they have spent money on this. We want to know what has gone on.' Or there could be a family member who has been overseas and come back and thought something is not right; we need to look at what is going on. I cannot think of any instances where it has been right at end of life because it is often too late then. To investigate it may take too long. To tear a family apart at the end-of-life stage is -

Ms OGILVIE - You are careful about that?

Ms SPONG - Yes.

Ms OGILVIE - Are your decisions published?

Ms SPONG - Yes.

Ms DAWKINS - With enduring guardianship, can there be an aspect of that which could be the advanced care directives or is this purely financial?

Ms SPONG - An enduring guardianship is not financial. We were talking about enduring powers of attorney; they are financial. An enduring guardian is lifestyle, health -

Ms DAWKINS - That can be related to the advanced care directives?

Ms SPONG - It can but the advanced care directive is not a legal document.

Ms DAWKINS - It does not have a legislative basis?

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Ms SPONG - No, and it may contain things to be done that are not legal. Therefore -

Ms OGILVIE - It cannot be binding?

Ms SPONG - No. Some people send them in attached to their enduring guardian and we keep it with the enduring guardian document.

Ms DAWKINS - How easy is it for somebody to change it? If it was someone who liked to be in front of the game and get something done in their middle age and find out, as the years roll on, they would like to change that, is there something that is a living document?

Ms SPONG - You can make an application to revoke. Many people find they have nominated two or three. You can nominate two guardians and an alternative on the document. You could nominate as many alternatives as you want, but realistically only one person or the first two are going to make the decisions. If you have a family falling out or that person dies, you can revoke a person or you can apply for a new one which overrides your previous one.

Ms DAWKINS - It is a bit like a will, in that sense?

Ms SPONG - Yes. It always overrides the previous one.

CHAIR - Donna, the interplay between what appears to be a fairly old form of document, the Enduring Guardianship with the advanced care directive and now the Medical Goals of Care, have you seen that interplay? How does it work, which one has priority, or have we made the process complex that is difficult to manage?

Ms SPONG - I can only speak from what has happened with our office. The enduring guardian is the legal document. It does not matter what your Medical Goals of Care you're your advanced care directive is. It is more a question for a medical person. A doctor has a duty to preserve life. His/her duty of care depends on what the person responsible, under our act, is saying, or if there is an enduring guardian, what the guardian is saying.

CHAIR - In the scenario Andrea outlined, someone had made an enduring guardianship and circumstances changed. If we have evidence of changed circumstances and people make slightly varied decisions, the complexity of going back to the enduring guardianship, varying it and having it re-signed and registered, is quite a length procedure. Is that correct?

Ms SPONG - You could do it in a day.

CHAIR - If you were fit and able.

Ms SPONG - Yes, but if you have lost capacity you cannot file it, so it is too late. If there is medical evidence that you no longer have the medical capacity to make your decisions in that time. Therefore, the one previously registered when you were of sound mind is the registered file.

CHAIR - Let us say that someone has capacity. We are talking about palliative care. We are talking about the terminal phase. That is clearly the most critical period, when a lot happens.

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If somebody chooses to either make a decision to end their life earlier, or to continue to have continuous care for as long as possible, if they make a change to what was their decision in their enduring guardianship, how easy is it for them to change?

Ms SPONG - You are saying that they are going to make that decision, which means they still have capacity.

CHAIR - Yes.

Ms SPONG - So the enduring guardian does not come into effect. They still have capacity to make their own decision. They have to have lost capacity for the enduring phase of the enduring guardian to commence.

CHAIR - Right, okay. That clarifies it.

Mr JAENSCH - An enduring guardian is a person?

Ms SPONG - Enduring means, it is an enduring phase, and guardian is the person you have nominated.

Mr JAENSCH - Yes, there is an appointment form that identifies the person who I want to make my enduring guardian?

Ms SPONG - Yes, we call it an instrument.

Mr JAENSCH - Does that instrument have provision for any other direction?

Ms SPONG - You can write in it, attach to it, whatever you want. Whatever decisions you want to have made, where you want your ashes, what you want to happen to your pets, people write anything. A lot of people write nothing. Most people write nothing.

Mr JAENSCH - My question is, pardon me if you have already answered this question, are the person's wishes then binding on the person who is appointed as enduring guardian?

Ms SPONG - Yes. It is in the act. It is as if the people were making the decision themselves. They are making that decision because it is what they know that person would have wanted.

Mr JAENSCH - Okay. If I am appointing an enduring guardian to make decisions on my behalf when I am no longer able to make them, and I am writing down what all those decisions are going to be, is there an option that I can lodge my wishes without nominating an enduring guardian?

Ms SPONG - No. In the past you used to be able to nominate the Public Guardian. I am not aware why, but quite some time ago that was taken away. I don't know whether it was a function the Public Guardian at the time could not manage. If we do have old ones where the Public Guardian was nominated, which doesn't directly answer your question, we notify the Public Guardian and they seek information as to whether there is someone in that person's life who can do it.

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Mr JAENSCH - If an advanced care directive is lodged as part of this instrument that appoints an enduring guardian, then that advanced care directive is binding on that guardian? That is a statement of the person's wishes.

Ms SPONG - Yes, it is, but it depends if the advanced care directive says something that is not lawful.

Ms OGILVIE - Then of course it is not lawful.

Ms SPONG - Yes. Medical advances, and I am sure -

Ms OGILVIE - Contexts change.

Ms SPONG - Yes.

Mr JAENSCH - That is why I am asking. We have said that it is binding on them, but we have a human there. There needs to be a decision that takes account of things. What is their room for discretion when they have the person's wishes?

Ms SPONG - If they have medical advice against what is there, they would have to make a conscious decision with their capacity and knowing the person as to what needs to be done.

Mr JAENSCH - I note that enduring guardianship sometimes sits in a situation where there may be differences of opinions amongst family members, but someone has been appointed. If they then act in the person's interests, but differently to what their wishes have been, where are they legally placed?

Ms SPONG - If they have medical advice and it is reasonable. If, for example, a doctor is at palliative care at the Whittle Ward and family members are arguing about what is in the enduring guardian plan and what the guardian has decided to do, the doctor would ring us and ask us to review that enduring guardian and put an emergency guardianship in. That is an emergency situation that would happen very rarely.

Mr JAENSCH - When you say review the enduring guardian, is that the form, the instrument, not the person?

Ms SPONG - It is to review the person who is appointed as the enduring guardian. We were talking about the powers of attorney, you can also review the enduring guardian at any stage, if any family member thinks the health and lifestyle decisions of the donor are not as the donor would have wished, or there is some issue with it. For example, if you were going to put them into Mary's Grange and you know they hated Mary's Grange, they would come and review it and say that the guardian is not making the right decisions on behalf of the donor.

Ms OGILVIE - I just want to get really clear -

Ms SPONG - So do I, and with different terminology.

Ms OGILVIE - I have just been through this process with one of my parents. It is my understanding that we have the capacity to prepare a power of attorney. That is a \$90 fee for registration; is that right?

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Ms SPONG - I think it is about \$130 or \$135.

Ms OGILVIE - That is prohibitive. An enduring guardianship document, which may include some commentary around what a person may or may not wish, by way of medical interventions or to prevent medical interventions. What we have been calling an advanced care directive is an invention of the medical community to assist them to provide a better understanding for those who might be providing care but which has no legislative basis. That goes to Roger's issue of, if you do not have someone you trust and love to stand at your bedside, who are you giving those directions to? That may be a reason that is coming into being. Am I right in what I am saying there?

Ms SPONG - I might just add something. Someone like myself, I am an only child, I have one child, I do not have anyone I could nominate as a guardian. I am happy for a doctor to make that decision because the doctor, in my belief, will make the right decision. It is only the other people out there who have a different opinion to me that wants to make sure. I think people as they are getting older are more concerned about these sorts of things and it is the older generation, older than me that want to put it down in. It becomes very confusing because they keep changing the guardian's name and worry this son, no get rid of that son, we will have this daughter. It does make it complex for older people.

Ms OGILVIE - I have a second question on the same topic. That is exactly what I am hearing as well as I move around the electorate with the older set in Tasmania, many of whose children are living interstate. So there is a Tasmanian problem which is a disconnect with the generations and the issues of people being interstate. In your mind is there a way to simplify the current arrangement under your act? Is there work we could do that would improve the scenario Roger's alluded to about who do I trust to make a decision if I cannot actually appoint someone? How do I articulate?

Ms SPONG - I do not have any suggestions.

Ms OGILVIE - We need law reform ideas for this one.

Ms SPONG - There is a review of our act coming up so it may be addressed.

Ms OGILVIE - Thank you.

Ms SPONG - Having emergency guardianship orders work, I do not know if you -

Ms OGILVIE - Do you want to run through those?

Ms SPONG - There is a review.

Ms OGILVIE - That would be helpful.

Ms SPONG - If anyone gets knocked over by a motorbike accident, they are in the Royal, they are unconscious, they do not have capacity. I do not want to go into specifics but there is a partner who is taking money from the person, their pension money. They get sent off to Heidelberg because they have spinal injury. They do not have an enduring guardian, they are only 20's or 30's so the hospital then contact us. They know there are problems and no one has

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been to see him and we put in an emergency, probably guardian and administrator. Then the Public Trustee and the Public Guardian for 28 days and manage the consent if they are in a secure area. They manage all of that.

In any situation the emergency orders seem to be sufficient and manage where there is not anyone or where there is someone not doing the right thing by a person. You hear of people going to the Royal and family dispute saying they should not be there and they should be taken out. There was someone assaulted recently in hospital and it was a family member who wanted to take them out of hospital. It was beyond the doctor's authority so we had to appoint a guardian to secure them in hospital until they had received the treatment.

CHAIR - Could you clarify for me, a guardian appointed in the instrument, they must be a resident in Tasmania?

Ms SPONG - No.

CHAIR - They can be interstate or overseas?

Ms SPONG - Yes, maybe that is something that should be looked at. I have one at the moment and there is no address, no phone number, so why pay your \$65. That person is travelling here this week or next week from overseas because her father is in need of a guardian but will not have the medical capacity done. Hopefully that will get sorted out, otherwise he will end up in hospital. The emergency guardianship will take over then because there is no one if the daughter is not here.

Mr JAENSCH - Who triggers the need for there to be an external guardian? Is it when someone turns up in hospital and there is paperwork done?

Ms SPONG - Yes, or there are a lot of people in Home Care. People in Home Care are being visited two or three times a week and often they will report back to Community Health Centre or Rural Health, whichever. We have had police nominate two or three in the past 12 months or apply, because these people are at risk. They do not appear to have capacity and through one way or another we manage to get the health care report and an application so we can get someone to care for these people. There are some sad ones out there.

Mr JAENSCH - Oh, there are.

Ms OGILVIE - Coming back to this and I give credit to Roger for raising this issue, of someone who is solo - this is really where the rubber hits the road - and/or is in a situation not optimal and have somebody who is doing the wrong thing. Apart from the interaction with hospital, hospice or medical providers, what do we do as a community or through the board to help facilitate better outcomes around the financial side of things? If somebody came to you and said, 'I see what's happening with my neighbour. He's an elderly gentleman with dementia and the young person next door has got hold of pin numbers to bank accounts.' If that story was brought to you, what power do you have?

Ms SPONG - Unless the person was going to make an application -

Ms OGILVIE - Is it a police matter?

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Ms SPONG - It can be. Sometimes there are stickybeaks. We get that a lot.

Ms OGILVIE - I appreciate that.

Ms SPONG - You get someone who will ring up to show you how far they are prepared to go, well that is stealing. Is it stealing or is it not? We have had a few instances with the police because it is very difficult to prosecute.

Ms OGILVIE - It seems to be a real issue. I have been speaking with the Council on the Ageing Tasmania about this economic abuse issue.

Ms SPONG - It is a matter of our investigators having a talk to who we know. If we know the doctor usually the doctor is the best.

Ms OGILVIE - They have the pulse.

Ms SPONG - But there are a lot of people out there who do not go to the doctor. There was someone who all their money was going to someone to buy drugs.

Ms OGILVIE - I have heard some terrible stories.

Ms SPONG - Hopefully everyone has a doctor or someone who sees something is going on, because anyone can apply. It does not matter who the applicant is. We can verify what they have said and then go from there.

Ms OGILVIE - So the GP can be the frontline in all of those issues.

Ms SPONG - Quite a few GPs are applicants. A lot of GPs do not assist though.

Ms OGILVIE - The complexity of life.

Ms SPONG - I think they are protecting the person. I have been this person's doctor for years, no I am not going to, so they choose not to provide the health care information.

CHAIR - Donna, this is my final question. If an emergency guardianship is put in place does the emergency guardian, I assume that is the Public Guardian, take into account a care directive and the medical goals of care?

Ms SPONG - Where would they get them from?

CHAIR - One would assume the doctor would have those, or the treating hospital, or whoever.

Ms SPONG - That is the problem. Nobody knows where they are.

CHAIR - Really?

Ms SPONG - I don't know. My mother is in a nursing home and I know that nursing home has asked me questions about it and they keep something on the file, but I have never signed that as formal directive. Is there a formal advance care directive?

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CHAIR - Yes, there is a formal document.

Ms SPONG - It is a piece of paper.

CHAIR - The medical goals of care is what doctors use to determine what care people have in hospital as they enter, so there is no interplay.

Mr JAENSCH - Unless someone attaches it to the instrument.

Ms SPONG - There is the enduring guardian, but surely if I nominate someone as my guardian, surely I am going to talk to them about what I want.

CHAIR - In the emergency guardian situation -

Ms SPONG - In the emergency guardian, no. The guardian can consult with the doctor. The guardian can talk to the doctor but they would also talk to the family members as well. It is not as if they go off on their own and do their own thing. They talk to whoever is involved. Even if there are six family members and they are all objecting to different things, they are going to try and listen to them all.

Mr JAENSCH - On this issue, you mentioned a review of the act coming up.

Ms SPONG - Yes.

Mr JAENSCH - As you understand the legislation, and you said previously there had been a public guardian.

Ms SPONG - There is still a public guardian.

Mr JAENSCH - Would it be a complicated thing for there to be inserted, if it was raised through and it survived the process, the ability to make your board the holder of a registered advance care directive for a person.

Ms SPONG - We see it as the same thing as an enduring guardian. It is introducing another layer and another complexity.

Mr JAENSCH - So we have a mechanism for that.

Ms SPONG - Yes, but it adds another layer of complexity. It is hard enough for a guardian to make a decision sometimes at end of life, and adding another document to an existing makes it more difficult, especially if there are two guardians and they both have to agree on one thing.

Mr JAENSCH - Yes, so having those wishes would be at least a guidance to them.

Ms SPONG - Maybe, or it may make it more complicated.

Ms OGILVIE - Every situation is so individual.

Ms SPONG - Yes, that is right. So many situations.

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CHAIR - I would like to draw your attention to this document that was tabled for us today. It explains the difference between the medical goals of care, advanced care directive, and enduring guardianships. That is put out by the Department of Health and it is a current document.

Ms SPONG - Someone found on a website information about the guardianship board which was not correct as well.

Ms OGILVIE - It is about having a legislative basis. We can design whatever forms we like, and that is all good and helpful, but if it came to a determination between the two documents, the one that has the legislative basis has primacy.

Mr JAENSCH - And we the only state that does not have a statutory basis to our advanced care directives.

Ms OGILVIE - That is right. That is why it is a little more complicated in people's minds than perhaps it ought to be.

CHAIR - Thank you very much for coming in to see us today.

THE WITNESS WITHDREW.

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Mr MARK BROWN, STATE DIRECTOR, AUSTRALIAN CHRISTIAN LOBBY, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED VIA TELEPHONE.

CHAIR - This 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 the fear of being sued or questioned in any court or place out of parliament. It applies to ensure the 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 the parliamentary proceedings. This a public hearing. Members of the public and journalist are present and this means your evidence may be reported. It is important that, should you wish all or part of your evidence to be hear in private, you must make this request and give an explanation prior to the giving of the relevant evidence.

Mr BROWN - Thank you very much for the opportunity to make a contribution. This is a very important inquiry and we appreciate the opportunity.

Ms OGILVIE - We have had what I could call a very fulsome series of committee hearings and we have heard from a lot of people around these topics of end-of-life planning and decision-making. We have just been listening to information this morning around advanced care directives that sit within the medical system, as opposed to powers of attorney and enduring guardianship documents, which are registrable documents under the Guardianship Board.

I was posing a question around what happens when there is an emerging elder financial abuse scenario and how we deal with that. It is allied to what we've been talking about, but it goes to the question of whether advanced care directives should have a legislative basis and what that might look like. Do you have some views around those issues and could you share them?

Mr BROWN - I am looking on page 3. The idea of a health care proxy is something we support. There is always going to be the potential, when you are dealing with humans, for things to go wrong. This whole aspect of elder abuse is a real concern, in that particular stage and in general. These most vulnerable people who are often unwell and at the end of their lives turn to those closest to them to look after their best interests. Sadly, you would expect family would be the best group of people they could turn to, but as we are seeing with the huge levels of elder abuse through the Helpline in Tasmania that it's not always a certainty. I was looking at an article in the *Mercury* where between 3000 and 4500 Tasmanians are, at any time, experiencing elder abuse. The hotline estimated, from what I previously read, on average one per working day.

The advanced care directives, as we mentioned, we don't believe they should be binding and we have listed a number of reasons why. Having a health care proxy is, in our view, still a worthwhile thing to do, particularly when people get to the stage that they are not able to make rational decisions for themselves. I suppose the question of whether the person they have chosen is making decisions in their best interest, we have to take that on face value. There is very little alternative.

Ms OGILVIE - I have been thinking about whether you would try to separate the person responsible for the health care decisions from somebody who would be responsible for economic and financial management of affairs. There is potential for conflicts of interest to arise if the same

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person holds those two elements. I am not sure how you deal with that if it is the trusted daughter, the trusted friend.

Mr BROWN - That's right, because they are often very much aligned. Most people in a family, if there is a will and finance involved, there is going to be some level of financial advantage from someone's passing. That is the way it is. The conflict of interest is likely to be there unless the proxy is somebody completely outside the family.

Ms DAWKINS - Through this inquiry we have heard from a lot of people that whilst it is improving our understanding of death literacy and our conversations in the community about advanced care directives and end-of-life care, would you say there is a greater role for the church to play in speaking to its members about when you have that conversation with someone?

Mr BROWN - Yes, and that is a very good point. A lot of the different organisations that look after people at the end of life period at domestic homes or private hospitals have that safe element in them already. At a church level, it is a very valid point that those within congregations who are in the upper end of their age bracket, should be encouraged by those in the church leadership to consider thinking about end-of-life care and planning. I am sure you have heard over this whole inquiry that communication is so important. The last thing you want to do is leave it too late.

Ms DAWKINS - Absolutely. There is some suggestion that speaking to somebody who is not yet ill, who might be in full bloom of middle age, rather than making it something that could be depressing or seen as negative, a nice conversation for somebody in a church situation to be able to have.

Mr BROWN - That is right, particularly from those with a Christian world view. Death is a step into the next world and it is not something to be fearful of. I think you are right. That should be a natural part of our conversation and even part of the common preaching topic, to talk about death and the whole death experience. It is very valid.

Ms DAWKINS - Thank you.

Mr JAENSCH - Hi Mark, how are you?

Mr BROWN - Hi Roger, doing well, thank you.

Mr JAENSCH - Thank you for joining us. In your submission on page 3, back to the discussion you were having with Madeleine a moment ago. At the bottom of the page you refer to the health care proxy; you use that term and then refer to durable power of attorney. We are becoming aware of a range of different legal or statutory approaches to this, here and in other jurisdictions. As Madeleine was alluding to, this notion of power of attorney in the Tasmanian context, at least, refers more to financial affairs of a person and maybe some of these other life and wellbeing matters might be more correctly dealt with enduring guardianship, under our current legislation.

Could you confirm what you are intending here, or if there is some other notion of a proxy that you are aware of that we should be adopting to do this better?

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Mr BROWN - Thanks, Roger. It is not altogether clear. Some people do not have family or someone they feel they can completely trust to take that role, whether it is an enduring power of attorney or whether it is a health care proxy. That begs the question: what other options do they have? At that stage it would boil down to a range of decision makers looking at the case. If we are having the conversation well ahead of the end of life, for a particular situation, it is worth considering. Do we want to separate those two roles completely? It may be the health care proxy could be a family doctor or someone who has had a relationship with the person for a number of years and they feel comfortable with, but having no immediate connection, such as being a relative.

The enduring power of attorney has a legal oversight but I also felt - I could be wrong - that when it comes to medical decisions, if that person who is unbalanced is not able to make a decision on their behalf, then that enduring power of attorney is able to step in in that case. Maybe it is something that needs a bit more clarifying as to whether they are separate roles or whether they could be separate roles if someone were given that option to say, 'Would you like both?' as a choice, rather than just the one.

Mr JAENSCH - As an extension of that, are you aware of circumstances, or could there be circumstances, where some of that role might be seen as a valid extension of the pastoral care a person may have in their faith group, because sometimes that might be the place they turn to for comfort and support and where they have trust in their lives. Do you see a role for the church in this stage of people's lives?

Mr BROWN - Yes, definitely, particularly if there are some who do not have family or do not have those intimate connections that we all take for granted. The church communities offer that level of friendship, which I think is an attractive thing for a lot of people in the community. Having a priest or pastor whom they trust and know has their best interests in mind, certainly it would make sense that they could approach them to be one of those healthcare proxies or enduring power of attorney. It makes complete sense. As Andrea mentioned, that could be part of that discussion within those communities at that time to make sure that all those things are very clear.

Mr JAENSCH - Are you aware of circumstances where a priest or a pastor has taken on the legal responsibility of being a guardian?

Mr BROWN - No, I am not aware. It may be a reflection of the fact that I don't get around enough or it may be more a reflection that those conversations are not being had and therefore it is a prompt to say maybe that's something the church in general needs to be considering further.

CHAIR - I want to draw your attention to the case you highlighted in your submission of *Gardner v BWV* where you say that the removal of the peg was not defined as a criminal act and the definition was a Victorian act - the Medical Treatment Act 1988. Do you know whether a similar definition applies in Tasmania?

Mr BROWN - It basically becomes a case law, because the precedent has been set. If there ever was a case similar anywhere, they could revert to that case and look at the precedent that has already been set. That is our major concern and why we are suggesting there needs to be a new statutory definition to ensure that, if that was ever a problem, then whatever is written in our statutes would override that.

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CHAIR - To give me an understanding of what you are intending to seek here, if the peg is defined as, or the food and hydration it provides is considered, natural - I gather that is what you are saying, as opposed to a procedure -

Mr BROWN - Yes.

CHAIR - then anyone removing that at any point would be considered a criminal act?

Mr BROWN - No. If you look further up we have talked about what is futile and burdensome; it is important to take those into consideration. When something becomes futile, maybe they are not assimilating the food or the fluids, then that is obviously completely different to when someone is saying, 'I have just had enough and I do not want you to feed me anymore'.

That is the difference, because they have still a hope of recovery and they are not just feeling like they have had enough of all the intervention; that is quite a different thing. If it is futile or if it is burdensome, if they are not actually assimilating and it is becoming a burden, if it is a nasogastric thing, and sometimes in a way they cannot even talk, then both things you have to take into consideration.

CHAIR - If the person had sufficient capacity and communication skill, if I could paraphrase what you are saying, and requested this to be removed, you would want to see that they could do that. That they would not be, in other words, force-fed.

Mr BROWN - What you are suggesting, I think, may be basically starving. If they are well in the sense that there is potential for recovery and it is not futile, the fact that their body assimilating it and it is not burdensome but they have just had enough, then that is almost like saying I want to die by starvation.

CHAIR - Yes.

Mr BROWN - That is not what we are saying, no. It is complicated in the fact that someone could just stop eating, but while they have a peg in place, for instance, I think to give into someone's demand to have it removed when they have the potential to recover or it has not been futile or a burden, then I do not think that is correct.

Mr JAENSCH - The potential to recover that you just referred to in that discussion, is that something which would be clinically determined, or while their body was assimilating food there is hope?

Mr BROWN - It depends at what stage the intervention is. Is it focused on healing, or is it focused on palliative care? Depending on where they are in that whole process, that focus would be seen differently. This is all very complicated because you are thinking of a whole lot of different scenarios or potential scenarios, but if you are focused on this person getting better then obviously there is no question. If it is a palliative situation where there are only a matter of days that this person is likely to live, then it has a whole different focus.

Ms OGILVIE - I am interested in the ethics around the end-of-life decision from you and your group's perspective. Early on in the piece we heard commentary around the doctrine of double-effect, which is also a legal doctrine but certainly an ethical issue. Having read your submission I see and understand that euthanasia is not, in your view, the answer. Could you walk

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us through the ethical framework of that doctrine of double-effect, that dying is already occurring and if an unintended consequence of additional medication is to hasten death then that is acceptable within the ethical framework. Do I have that right?

Mr BROWN - Yes. That is basically what we have always stipulated in any of our submissions. Really it is the intent that is the key. The primary intent is to alleviate the pain or make someone comfortable. Then there was the secondary consequence of hastening death, then that is not considered to be euthanasia. We have always stated that but there is a lot of confusion in the community. That is why this inquiry is great

If there was legislation that would very clearly define what is and is not euthanasia and what is and is not considered palliative care, it would be a very useful thing because we do not need to look very far in the community to get a lot of confusing ideas about turning off life support system being euthanasia for instance.

It is very important it is made clear to everybody what we are talking about when we consider this end-of-life care aspect.

Ms OGILVIE - Thank you Mark, and thank you Chair.

CHAIR - Mark, thank you very much. I really appreciate your coming on line today for us and your submissions. Do you wish to make a final comment?

Mr BROWN - No. Once again, thank you for the opportunity. It is a very useful discussion to get the community talking about this. I know you have heard from so many already and it can only do good, so well done. Thank you, Madeleine, for opening the questioning.

CHAIR - Very good. Before you go, as I advised you at the commencement of your evidence, what you have said to us here today is protected by parliamentary privilege. Once you leave the table/telephone, you need to be aware privilege does not attach to comments you may make to anyone including the media, even if you are repeating what you have said to us. Do you understand?

Mr BROWN - Yes.

CHAIR - Thank you very much, Mark. We really appreciate it.

Mr BROWN - Thanks everyone.

THE WITNESS WITHDREW

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Dr PETER SAUL, SENIOR INTENSIVE CARE SPECIALIST, HUNTER NEW ENGLAND HEALTH, WAS CALLED VIA TELEPHONE LINK, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Those of us that were able to see your presentation found it very useful and helpful, so many of us have seen it. Would you like to make your opening statement, please.

Dr SAUL - I just wanted to say two broad things. One is about terminology. One of the problems we get into with end of life in general is using terminology we all agree means the same thing.

There are just four terms that come up and I wanted to clarify my use of them so everybody else knows when I say something what I mean by that.

The term 'palliative care' in New South Wales generally means specialist palliative care, even if you do not use capitals for it. We tend to use the term 'palliative approach' or 'palliative intent' if we mean a broader thing than specialist palliative care. I just noticed in your title it was an inquiry into 'Palliative Care' capitalised.

The second term is 'advanced care planning' which I regard as an umbrella term used at any stage of an illness and may be quite an informal process. It may be just even a conversation. Advanced Directives is more specific. It means two different things. One is their so-called living will where there is an actual document produced by the patient says in the event that I do not want this, which is the general format. There is an alternative, which is the appointment of a health care proxy with or without instructions. I would regard those two things as being separate, although the national framework lumps those together into Advanced Care Directives. I would call those two things a separate thing.

The third terms is the 'goals of care conversation'. The goals of care conversation is for seriously ill people and it would include a recommendation and may result in treatment limitation on medical orders, such as a resuscitation plan or a goals care plan signed by a doctor not by a patient. It is a different thing from advanced directive or advanced care planning.

I am just making clear if I use those expressions that is what I mean by them.

The only other point I wanted to make apart from the terminology is the evidence we have, at least from New South Wales, is the main problem in managing end of life broadly is the coordination of care for people who are in the last year of their life. We have now data showing they have an average of 105 contacts with the health system in that year. The main problem we have in improving their care is the lack of coordination of those individual contacts.

Another stand out intervention in the world dealing with this at the moment is a project in the UK called Coordinate My Care, based in the Royal Marsden Hospital in London, but now rolled out to the whole of London, which is quite well evaluated and shows the coordination of care is the only thing that really has made a big difference. I am not declaring an interest in saying this, but I am part of a group that has received \$2 million funding from New South Wales Health to try to institute that in my local area as well. Coordination of care is something that I have some stake as a strategy to improve people's experience.

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Mr JAENSCH - What is that project called, please?

Dr SAUL - The one that we are doing locally, you could find it under the Hunter Alliance, which is an alliance between GPs and the health service. My Net Care is our name for it.

Ms DAWKINS - I would like to make an apology, I am just reading something you have said here:

It is time to put aside such token gestures as inviting submissions from the public to inquiries.

For that I do apologise. Thank you so much for coming anyway.

We have heard a lot about the lack of death literacy amongst our medical professionals. Do you think we are getting better at talking to new health care professionals about having those conversations with their patients?

Dr SAUL - I would like to think so but I cannot point to any real evidence for that. I totally agree that health literacy about death starts with people in the profession. We have held focus groups with our local community. They say they expect we will initiate conversations about end of life and that we will be well informed in that area. I do not think that has been the case.

A study in Queensland showed that of 487 specialists interviewed, only six could give an account of the law at end of life in their own jurisdiction. That was published by Ben White at the Queensland University of Technology.

The level of knowledge in doctors is low. The level of willingness is extremely variable but does not seem to increase with the junior status of people. The fact you are somebody young or new, does not mean you are more willing to talk about end of life. It requires that we intervene with doctors a lot more to make them more willing to do this.

Ms DAWKINS - Thank you.

Ms OGILVIE - Dr Peter, thank you for coming online all the way from sunny Sydney. I am one of the Labor members on this committee and have a legal background. Your comments around the complexity of end-of-life decision-making and the legislative framework around advanced care planning resonates very much in the Tasmanian scenario where we have common law, along with other legislation. We have been giving a lot of thought to how we improve that.

One of the things you have written and I was very taken with, you have identified five key factors in a good death. It speaks to me of the dignity of how we would all like to shuffle off the mortal coil. You talk about not prolonging the death, to maintain control of the timing of things during that process to alleviate suffering, to take care of the family or relieve the burden of the family. You also talk about strengthening relationships.

In the context of the great complexity of this issue, could you flesh out that philosophy a little bit, about how that good death looks, or how we can achieve it for more people?

Dr SAUL - It is not a term I recommend to be used widely. There is nothing that good about death even in the best of circumstances. It is always sad and sometimes bad. We need a better

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phrase. I do not know what that phrase is. Ken Hillman talks about dying safely, as a patient safety issue rather than whether it is good or bad.

In terms of what would be the qualities of good death, the fact we lack such a metric makes it very difficult to do quality improvement well. We cannot point to a death and say that was a good death, in any realistic way. I will talk more about the fact that we should.

The overwhelming element people talk about when they talk about a good death is the patient had some control over what happened. It is a very strong theme that comes through all the literature on a good death, is that the patients have some input into the way that occurred. This has been picked up, wrongly I think, by the euthanasia lobby. We can talk more about that. The notion the patient is respected, it seems very important they have dignity. Those terms both mean they are treated as an individual, which means they then have some input into what happened.

The area where the law has failed to grasp the nettle is in exactly how it is patients come to exert some control over what happens to them; what is mandatory in terms of what is recorded about them when they go into hospital; what is mandatory about what forms are filled in, how and who is open to; the status of statements made by the patient, how they are documented and reacted to by the hospital, and how that is audited.

We have not grasped the nettle fully of dealing with patients' own viewpoint about how they should be treated. Doctors on the whole are very dismissive of advanced care plans broadly, and the directives in particular. Most emergency departments say they are not worth the paper they are written on.

Some jurisdictions have responded by legislating. South Australia has been the most aggressive in this. All this does it drives people to not want to do it. In Victoria there is a refusal of treatment. You rarely see them. Only about 20 a year are given to the Public Advocate in the whole of Victoria. The problem with the legislative approach is it scares people off a little bit.

I am not unhappy with the common law approach but what we need to do is make it much clearer, what the legal status of these documents is and how the hospital has to respond to such documents if they are presented with them. That is part of the process that all the hospitals in Tasmania or wherever, would all do reliably and people can rely on that happening.

Ms OGILVIE - So better conformity or better communication about the nature of the documents, there could be some sort of registration capacity? Are those the sorts of things you are thinking about?

Dr SAUL - The only country I know that has tried registration of the documents is Spain. It seems to be working for them, from what I hear. The end intent is to have an electronic medical record where most documents are filed and the Coordinate My Care project in London I mentioned, and the one we are doing locally, does exactly that. The patients lodge documents they want to be seen onto this website. Registration is something certainly worth thinking about.

Ms OGILVIE - Thank you.

Mr JAENSCH – Peter, thank you for an article we have seen of yours on *The Conversation*, very well put.

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If we are going to have something universal and meaningful enough to be there for everyone when they need it, and somewhat standardised or reliable as evidence of a person's wishes, how else do we deal with it if not through some sort of statutory mechanism?

Dr SAUL - Yes. I think all states have wrestled with it, most recently WA. The problem with a legislated form, as I say, is that people are somewhat scared off by the sheer legality of it. It is also unclear what that does to all the other common law things that they may have done, the conversations they have had, the other things they have written down. You cannot really set aside the common law, even in legislating.

It probably is not as useful as it seems. What we have come up with in New South Wales is a compromised position, which is to say we are not going to legislate the form. The Health Department has put out a recommended form.

I chaired with a group that looked at Advanced Directives of New South Wales Health. We decided we were not going to legislate the form. We were barraged by people who wanted the form. In the end we said we will give you a form we believe meets all the criteria we put into our guideline, but there is no legal compulsion to use that form. If you are going to use the form, this is what it should contain. This is an end model version of that.

That was the compromise we came up with. I am not pushing legislation of a particular form as being an answer. I do not think what South Australia has done is right. I oppose what they have done. There are a lot of unintended consequences. The idea of registration of such documents would be handy.

Tasmania recommending a particular format seems quite reasonable, without disenfranchising other forms that may come from other states, which is the other problem you have with legislated forms. You then have to deal with people who have used something different from somewhere else, or have downloaded it from the internet.

That is why we have been nervous about going with the legislated form. We are seeing quite a lot of that at the moment.

Mr JAENSCH - With the model you have adopted or you are working with, you have reluctantly given people the form so they have got some standard headings to work to. What do they do with it once they have filled it in?

Dr SAUL - That is a good question. There are two broad categories of people who do this, there are those who are in residential aged care and that is relatively easy. Residential aged care is doing very well with this locally. I do not know how it is working for Tasmania because life expectancy is quite brief on admission to residential aged care these days, probably no more than about six months. End of life has become quite a prominent issue and people are being encouraged to fill out such forms and they are being kept and sent with the patients when they come into acute care so we are getting those forms from residential aged care.

The problem with the broader community is the forms are generally kept at home and not readily available where you need them. Again, I keep going back to the Coordinate My Care and My Net Care and the intention there is to have an online access to any documents the patient chooses to upload. Certainly the federal electronic health record was working on the same lines as electronic lodgement documents being a more reliable way of getting hold of them with a few

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caveats. You have to make sure they are filed in date order, so a new document replaces an old document so people can keep changing it.

In the end electronic will turn out to solve many of the availability problems we have had so far.

Mr JAENSCH - Yes, I agree it seems ludicrous in this day and age we rely on having to find a piece of paper at the moment when we are moving someone into higher acute care when there are probably a lot of other things going on in people's environments at that crisis time.

Dr SAUL - With due respect to the lawyers, keeping the lawyers out of this turned out to be a major issue because lodging it with your solicitors is hopeless at 2 a.m. on Sunday. We are not going to find it at the lawyers and the law society has put a model form of their own for advanced care directions which actually makes no sense at all. They can just say, 'I do not want to be a vegetable' which is actually really useless.

Mr JAENSCH - Regardless of the format we send it in, it still needs to be sent somewhere, doesn't it? It has to be a logical place so when a person turns up unaccompanied with nothing but their identity, you can go find it.

Dr SAUL - One of my beefs with South Australia is they have said that your person responsible, which is a term I think you use in Tasmania, what used to be next of kin, but the person who is your medical decision-maker should be excluded from the process of writing your events care directives on the basis they have a conflict of interest. I see it is a 180 degrees the other way which is the person who is going to speak for you must witness and be involved in your advanced care directive because they are the ones in the end who will present it to the hospital on your behalf because they are the people they are going to call.

One legislated mistake South Australia made was in not recognising end-of-life care and decision-making is actually a family affair, not an individual affair. Having your family and person responsible aware of your wishes and ideally in possession of copies of your advanced care directive is actually a key to making them work.

Mr JAENSCH - Thank you.

CHAIR - Peter, could you clarify for me, is the registration of an advanced care directive one and the same as having it on an electronic health record? Are they interchangeable, or are we thinking of two systems?

Dr SAUL - No, I think they would be same actually. The more I think about it the more I realise we are exactly going in the direction. Our local project My Net Care references your national health identifier so we will have it if people start uploading documents onto our website. It will be picked up by the national identifier and would effectively be a form of registration itself. I get the whole registration idea Spain was doing will become necessary as we move more in the direction of an electronic medical record which in itself will function as a form of registration of documents.

CHAIR - In regard to the scepticism the medical fraternity have to advanced care directives that you have experienced, can you explain what the scepticism is about?

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Dr SAUL - Yes, this is a very widespread problem. Acute care is the source of much difficulty in end of life. We were talking about educating doctors and making sure that they are health literate. Their literacy about the role and status of an advanced signed statement by a patient is particularly poor. In those jurisdictions where there is legislation that makes such documents legally binding, they may or may not have the same difficulty.

In New South Wales the overwhelming response from the emergency department registrar is, 'This isn't worth the paper it is written on.' Principally they say, possibly not entirely inaccurately, if the family don't agree with it they will overturn it. We have never yet had a case in New South Wales that has gone to court where the family has said, 'No, we do not agree with what this patient has said in their advanced care directive. We are going to overturn it.' We have every reason to believe the family could, based on organ donation and other similar issues, if a patient is registered with an authority as a donor and the family has said no, we have generally gone with the family.

In New South Wales, and I think also in Tasmania, the family have legislated rights under guardianship provisions that are not matched by anything for patients. I think the emergency departments feel if there is a document a patient just signed and the family don't agree with it, they are in the deepest trouble if they go with it. They are generally very sceptical about them. I think that is why I say the most useful way of looking at an advanced care directive is as education for your surrogate decision-maker. The whole function of having an advanced care directive is to guide your surrogate if and when they have to make a decision about you, when you are no longer capable of making that decision for yourself.

The problem with promoting them as being a direct instruction to the doctors is that we run constantly up against this issue of having privileged the family in so many other settings, to make decisions for you. Everybody is bewildered when, all of a sudden, the family is left out. South Australia is an example of misunderstanding, in my view, what an advanced care directive is really for.

CHAIR - Do we need to have clarification between the role of the surrogate decision-maker and the role of the family, if they aren't one and the same thing?

Dr SAUL - That is another area of complexity. I haven't studied your guardianship provisions in detail. There is some question in New South Wales about the standing of other family members, aside from the one designated as the person responsible for making such decisions. In our Administrative Appeals Tribunal, non-family members have been given standing to bring cases before that tribunal. It was a business partner, on one occasion. We tend to think of surrogate decisions at end of life of being quite widely shared. The way I teach it at the moment in this context is that you must include the person responsible. That does not mean you exclude other members of the family. The process according to our guidelines is consensus building. That comes down to hopefully extending to as much of the family as possible. I realise it is becoming vague now.

There are a couple of precedents in New South Wales. When there has been a disagreement in the family, the one who was more clearly the person responsible was given the authority to make the decision, but we haven't really tested that widely. I tend to use the word 'family' when I talk about people close to the patient, because the law doesn't really make it clear where everybody else stands.

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CHAIR - If there was clarification between the role of the surrogate decision maker and family members do you think advanced care directives would be less sceptically considered?

Dr SAUL - I think that is one of the great virtues of any form of advanced care planning. The appointment of a surrogate gives that person control of who does make these decisions. I talk about the five daughters' problem. If you have five daughters, the chance of them all agreeing on what should happen to you are minimal. The great virtue of an advanced care directive or the appointment of a surrogate decision-maker is in fact to clarify who in the family has a view that more closely represents your own, which is in fact the outcome we are looking for as doctors.

Ms OGILVIE - I have been very impressed with local medical practitioners, particularly in palliative care, with their capacity to bring family meetings together to navigate a lot of that territory. It seems to me that what is done by way of that clinical operation is just as effective as any words on paper.

Dr SAUL - Yes, I totally accept that. The family meeting is the underplayed but absolutely key aspect of making end-of-life decisions.

Ms OGILVIE - You made an aside on having some sort of control over the end-of-life progress and that the euthanasia debate has overtaken those considerations. Can you flesh that out?

Dr SAUL - Yes. Either by design or by accident. The whole notion that we have any control over end of life has been adopted as being part of the euthanasia spectrum, which I don't think it really is - no more than controlling who you marry or what mortgage you take out is exceptional in any way.

We make decisions about health care all the way through and not just about end of life. Every time I talk about end of life they always talk about euthanasia as being the elephant in the room. In my view it is not; it is the mouse in the room that is being looked at through a magnifying glass. Even where euthanasia is legalised, whatever that means, it is a very tiny minority of people who take it up. We all have to die. For all of us, the sense of control over what happens is important.

It feels like we are disenfranchising 99.5 per cent of people by focusing on questionable legalisation of quite rarely used technologies, when really what we should be doing is minimising people's belief that they need to do this by generating a culture in which people feel they do have some control over what is going to happen to them and it is not all going to be undignified and awful at the end, which is the fear.

If you look at the Oregon Dying with Dignity website, they have kept fantastic data for 15 years about who has taken this up. They are saying they are white male university graduates who fear a loss of control. Intractable pain is less than 5 per cent of the reason why people kill themselves. The whole driving force behind euthanasia is about control; it is not about suffering. We do need to get on the front foot with this and actually say we accept the need for control; we do not need to say that means we legalise euthanasia. The two things are not synonymous with each other.

CHAIR – Peter, would you like to make any final statements?

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Dr SAUL - Yes, a couple of things. One is that we need better evidence for what we talk about. We started an audit of deaths in New South Wales. It started locally with us here in Newcastle and spread to the whole of New South Wales. When you talk about euthanasia and other things, they all claim that they are these people with intractable suffering but we cannot point to data that shows that to be true or untrue generally.

One of the things that I would really love, if Tasmania is seriously looking at this, is to recommend that deaths are audited. They may already be, but that some elements of that audit include quality of death as well as preventability. Actual evidence about how and where people are dying and in what circumstances would be incredibly helpful in guiding any future changes that Tasmania may want to make. We are doing it in New South Wales and I am very happy to correspond with people about how we are doing that.

The only other point I want to underline is that, while end of life is a community issue, acute care remains a really crucial aspect of whether that works well or not. Many people go in and out of acute care a lot during the end of their lives, and we have lots of data on that, but it is the culture of acute care that is making it so hard to die at the moment. Acute carers are sceptical about all changes that occur, all statements that patients make. We have a culture of cure in acute care that makes it very hard for people to accept that people might come in and not want more than just being looked after in a palliative way. Not everybody who turns up in hospital is implicitly consenting to have a laparotomy and go to intensive care on a ventilator. The data we have from the over-85s and so on is overwhelming that they do not come to hospital expecting that, but they have nowhere else to go.

If there is a perceived problem with end of life you cannot really fix it without dealing with acute care and the culture of acute care. People leave acute care out of a lot of things with meetings with palliative care and community palliative care and geriatrics. If you are going to have this debate it has to include people from acute care because they will derail anything in the end. Having been a derailer of note, I know this is true.

CHAIR - Peter, that was excellent evidence. I am sure we all appreciate it. Thank you very much.

THE WITNESS WITHDREW.