

## **PUBLIC**

### **THE HOUSE OF ASSEMBLY STANDING COMMITTEE ON COMMUNITY DEVELOPMENT MET IN COMMITTEE ROOM 1, PARLIAMENT HOUSE, HOBART ON TUESDAY, 9 AUGUST 2016.**

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#### **INQUIRY INTO PALLIATIVE CARE**

**Ms BRIGID McKENNA**, OFFICE OF LIFE, MARRIAGE AND FAMILY, ARCHDIOCESE OF HOBART, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

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

**Ms McKENNA** - Thank you for this opportunity to appear before the committee on behalf of the Archdiocese of Hobart, but in the capacity as the director of our Office of Life, Marriage and Family. The subject of this inquiry is very close to the hearts of the church so we have been very pleased to participate. We have, both here in Tasmania as well as globally, I suppose, a long and ongoing tradition of caring for people who are dying and for their families, which I believe has led to a significant body of accumulated knowledge and also ethical reflection, in particular, which was largely the subject of my submission to the committee. This is to say at the outset why we have always been so interested. It is partly grounded in our belief in the innate human dignity of every human person, but also motivated by our desire to share in what we would understand as the healing ministry of the church to very much accompany people and their families throughout their entire lifespan to a natural death.

**Ms DAWKINS** - We have been talking about advance care directives over the last day. What proportion of residents or patients who come to you have one of those in place, and are you able to use them in a really productive way or do you feel that you have to manage them and alter them as a person's condition changes?

**Ms McKENNA** - I understand that Calvary Healthcare Tasmania will be appearing and they are more directly involved in service provision than I am, so they will be able to give you an indication. I suppose I can say to you that from the broader perspective of the church, the way we speak to and inform our own people, we are very supportive of advanced care planning. You may have picked up from our submission that we have a slightly nuanced approach, but it would certainly be something we would be encouraging people to do. My role is very much one of community engagement and it is certainly something we would always be encouraging people to be thinking about. It is beyond just encouraging conversations with their families and friends to actually think about taking some concrete action. I think we are probably as slow as the rest of

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Tasmania and Australia in picking up that concept and starting to really think through it. I can't give you any specific answer but I know Calvary will be able to do so.

**Ms DAWKINS** - That's fine. As far as the ethical position of the church having a sense that the sanctity of life will always be cherished in every situation, if somebody wanted to have medicine and food withdrawn so they could die peacefully, is there anything ethically as far as church teachings that would stop that from happening?

**Ms McKENNA** - No. We are very clear about any treatment that is futile and no longer achieving its desired end or is overly burdensome, which is the language we commonly use. That is a very broad term. Obviously the most important thing is it being overly burdensome to the patient themselves, but we also encourage in that mix to be thinking about individual in society as well. It is thinking about the burden of the treatment to one's self, but also how it impacts on family and community as well. We try to encourage that discussion.

**Ms DAWKINS** - Do you think the subtlety and nuances within any personal circumstance can be managed in a way that fits with the ethics of the church?

**Ms McKENNA** - Yes, I think so. Probably one interesting distinction that we talk about is trying to really encourage focus on the burden of the treatment rather than the burden of life, the burden of the condition. For instance, when we are talking to other Christian people who we know share those values about sanctity of human life, it is about thinking about how the treatment is impacting - if the treatment is futile or the treatment has become burdensome - to avoid any sense we would be implying someone's life is futile or their life has become futile. That is a nuance we take a lot of care around.

We have had a thousand-year tradition of talking about treatment that is burdensome. We have used all different terms: extraordinary, ordinary treatment. We have tried to simplify our language in more recent times, and Catholic Health Australia has produced some documents to help people to be able to think in a much clearer way and to focus on those two very important concepts which are at the heart of Catholic ethical teaching.

**Ms OGILVIE** - Thank you so much for coming and it is wonderful to have you here. In the community there can be confusion around what is the perception of Catholic teaching around sanctity of life when it comes to end-of-life decision making, and the reality. We will hear from Calvary later on today, very practical people.

**Ms McKENNA** - Yes, absolutely.

**Ms OGILVIE** - My personal experience in going through at least one death that was close to me through the Catholic system was that it was handled extremely well. This idea of burdensome treatment helps people who are around that patient feel they are relieving a burden when they let go. It is a social thing.

Could you talk about that and how those decisions around end of life sit within the ethics of the church, to clarify what I think the position is, that it is okay to stop, that it is your right to cease and refuse any treatment and how that is handled? It would be worth having that on the record.

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**Ms McKENNA** - We are always trying avoid two extremes, both under treatment and over treatment. From our perspective, a Catholic Christian would see, yes, life is sacred, it is a gift of God but it is not God. Death is inevitable, death will come, and for many Christian people death is perceived as some release. It is a passageway to, we believe, eternal life. We ought not, as Catholics, have any great fear of death. That is something we try to foster amongst ourselves and something we would like to be sharing with the community. We are not vitalists. We would very much be encouraging people to feel they can still honour and uphold the dignity and beauty of human life by letting go when the time comes.

It has been a strength of our tradition in our hospitals for some time. Everybody fears death, that is a very natural thing, but that we have this other dimension to say it is okay to let go, that natural death is an event we will all experience, that it is something we can, and we ought to, prepare for so that letting go is in no way a rejection of the gift of life or rejection of other people. That would be very much a part of the human condition.

**Ms OGILVIE** - In Catholic health care, I presume palliative care, including pharmaceuticals, are managed in the way they would be managed in any other facility. It might be worth touching on the doctrine of double effect so we have your ethical basis for that before we come to the Calvary discussion. Is that okay?

**Ms McKENNA** - Yes, absolutely. Our tradition is embedded in Catholic ethical thought, but in medical ethics generally and the law is that we distinguish between events we foresee when we act. An outcome we foresee and an outcome we intend. The classic example, which I will qualify by saying actually rarely applies in modern palliative care, is if we were administering pain-relieving medication such as an opiate, like morphine, to a patient and our intention was to relieve the patient's pain and distress. Even if we could foresee that that might shorten their life, we would still be very comfortable and clear-minded that what we are doing is actually focusing on the patient and relieving their pain, and in no way intending to hasten their death.

We make a very clear distinction there, a distinction that has been reflected in medical ethics for centuries, as well as in our law. Many Catholics, not all Catholics, will have a pretty strong understanding of that. It is quite a recognisable part of our tradition, but we certainly find that we still continue to need to explain, particularly today when there can be some sort of fear of what a doctor or nurse might be doing to me.

It is something that we continue to speak to. I use the example of opioids. I qualify of course, you probably have already heard, in modern palliative care, as long as opioids are used well, introduced at the right time, increased in doses according to pain, evidence shows that they actually do not hasten death. That has been the classic example. We can also use the principle of double effect in terms of withholding or withdrawing medical treatment.

If our focus is on withdrawing a treatment that has become futile or has been experienced as overly burdensome, then we can do that even though we can foresee, sometimes with great certainty, that that will lead to death coming sooner for that patient. It is a principle that has held us in good stead for many years.

It has more recently been under attack as some sort of sophistry, but I think it is very workable, and certainly in my own experience as a clinician, it is how doctors think. We are taught at medical school even to think about that. Our focus is on the patient and what it is that we are choosing to do here and now.

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**Ms OGILVIE** - It is reflected in our criminal code as well, is it not?

**Ms McKENNA** - It is, yes.

**Ms OGILVIE** - Really it is part of the training around the intention and the act. They are two separate elements which protects doctors as well.

**Ms McKENNA** - Yes.

**Mr JAENSCH** - Thank you for your comprehensive submission, and thank you for taking the effort that you have made to present the ethical basis of the church's position. I think you have anticipated a lot of the associated discussions very well. My first question then is, how do you find the medical profession that you work with around this fine line of burdensome treatment and another tradition, I think, in medicine of life being the whole game?

We have come across that a bit. You have, as you said before, a more nuanced view, which comes down to intent and dignity and other matters. The point where a decision is made, where one thing overrides the other, do you find that you get pushback from the medical people that you interact with on this?

**Ms McKENNA** - No, I have not really. I can speak in two capacities because my background is in medicine and I have worked in palliative care. Obviously within palliative care I experienced very little pushback. In the setting of acute medicine, when you get off the roller-coaster and stand back and reflect, most clinicians are informed and are able to very clearly make the distinction, and they have been taught to do so.

Yes, I have certainly witnessed circumstances and situations which have been vitalist more or less. It is pushed. I suppose I would say of that that I believe it to be bad medical practice. That is in keeping with my own formation as a doctor and our own internal code of conduct, as well as a Catholic and someone who has studied ethics. I think there has probably been a bit of a shift but there is still tremendous scope. I suppose I speak here being able to tap into some of the vulnerabilities of health care professionals because there is this desire to do everything that you can. To a certain point that is a really valuable thing. That is what has led to the development of medicine, to the place that we are in, but it is very much a case of our own virtue, I suppose, to be able to contain that and keep the focus on the person, the patient, that is before us.

**Mr JAENSCH** - Can I flip it around and get another scenario that maybe you didn't anticipate but you might encounter sometimes? Do you ever have family members, say, who want you persevere and keep a person alive, at any cost, forever because it is their person? Do you have a tradition of counselling those members then to say it is time to let go?

**Ms McKENNA** - Yes, the focus needs to be on the dying person. In order to shift that focus you need to first meet with the family's own anxieties, their own fears, their own needs before you can redirect them. Within that then I think there are very emotional psychological issues that you need to deal with, as well making sure that people do understand, particularly if they are Christian people, that they are allowed to let go. So, there is information giving, as well as trying to address their own anxieties.

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**Mr JAENSCH** - In the commentary you have given us on the advanced care directives, I had the sense that in that process you don't feel bound by that person's wishes expressed at an earlier time so much as the judgment of the clinicians and of the proxy that the person has nominated at the time of final days.

Is that because the person couldn't have anticipated the circumstances? I read in that [what you've said] some denial of a person's will as expressed when they are competent to give it, in full knowledge of the consequences and their likely trajectory. I thought because there is a loss of agency there.

**Ms McKENNA** - You have got right to the heart of our approach. We would never override a patient's autonomy in that sense. I suppose because advanced care planning is stepping back and getting in early. From the outset we encourage a slightly different approach, rather than simply asking someone to compile a directive, we encourage them from the very beginning of the process, preferably, to appoint a guardian, perhaps to put in writing in a directive form -

**Mr JAENSCH** - When you say 'guardian', do you mean guardian in the full legal sense that the Tasmanian system offers?

**McKENNA** - Yes, it could be. It is a national document that I am referring to but here in Tasmania, yes. We do not want to see people feel that they must take a particular course, I suppose. We want some flexibility. They may not wish to go down that pathway but we would encourage them to do something beyond just writing a directive. I suppose is our approach, with a view to those situations that you have spoken of, where there is a real conflict of interest at the end, could be avoided. That said, if down the track here someone has an advance directive that clearly states their intentions and family are at odds with that, we would not override their express directive.

We are trying with our approach to start of the very beginning of the process, to remove some of those problems. So autonomy is very important to us. We would not override the autonomy of the patient, their express wishes, their declaration of values but we would encourage people from the outset to try to move away from just a solely autonomy-based model, partly because we think that does not really work well in the context of health care because of changing circumstances and the types of conflicts can arise.

**Ms OGILVIE** - A more iterative approach, more of a journey rather than a point in time.

**Ms DAWKINS** - What if somebody was alone and did not have anyone to make those sort of decisions with them?

**Ms McKENNA** - The sort of advance care planning documents we have - the forms allow them to make a written directive which they could lodge with their GP, but we would still encourage and hope to find a person to connect with early on. It is very much a process. I understand what you are saying - we are probably trying to take the weight out of the autonomy a little bit because we believe that ultimately dying and death are done better when we are working as families or units or communities.

**Mr JAENSCH** - Even the notion of having autonomy provides relief sometimes for people. This is a scary night we are going into but at least if you have some hand in it, it makes it less scary.

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**Ms McKENNA** - I agree entirely and that is why I say we do encourage an advance care plan. We want people to feel they are very involved in that stage; that they can plan, they can express their values and have them down and have some confidence. I think too it is important in talking to people to say that as you are undertaking the process of the advance care plan to think about your family situations and what they will be placed under. In some sense, it can be a way a of making a gift to your family, relieving them of some of the burden.

**CHAIR** - Brigid, I want to talk about advance care directives. I was listening to your words and I get a sense that you would prefer the document, perhaps, to be called 'advance care planning' rather than an 'advanced care directive', in the sense you would prefer it to be descriptive as opposed to prescriptive. The directive implies a prescription - it is binding; this is what I want done when none of us can predict what will happen when we are at that point.

In regard to that, you also mention that there is a legal right - and I am not a lawyer - how far does that legal right go when we have heard in evidence that an advance care directive has no legal status but you cannot refuse treatment in an advance care directive. Can you walk me through what seems a bit of a hodge podge?

**Ms McKENNA** -I am not a lawyer either. I am speaking here too as a clinician with some ethical background. Patients have legal rights and we have responsibilities to respect those. In those very difficult situations, doctors may be at a loss in that they feel that they too have lost a bit of their autonomy - not as something to exert over a patient but in terms of their professional autonomy. I can appreciate we lose something if we become too legalistic, if we start to talk about very much being a healthcare consumer, a healthcare provider; I have my rights. I suppose what I would see as the best clinical; the best caring environment, we are coming in as equal partners, acknowledging we begin with different vulnerabilities and different levels of expertise. I think, if we have a system that is so totally bound in law to protect the rights of the patient, we do risk that we lose something in terms of professional autonomy - a doctor's or nurse's capacity to care and respond to the situation as they see best. But then too we also have talked about vitalism. All health care providers have trouble letting go at times. We need to find some way of respecting and honouring clearly expressed patient wishes and values.

It is finding a line and I am not sure that the law is the best instrument sometimes. That is why we tried to start the process way back, at the very beginning, in terms of advanced care planning, but when it comes to the actual dispute, my legal expertise doesn't take me any further.

**CHAIR** - With the right to refuse treatment, how far along the spectrum does that go? If you have an advance care directive that indicates someone doesn't want treatment and perhaps there is no communication or you can't get to the essence of asking that person specifically, how do you deal with that?

**Ms McKENNA** - I think in those situations it will be very clear that if they have made a valid and clear expression that they did not want treatment in this circumstance and it applies, then irrespective of the surrounding people, we would be respecting that right.

**CHAIR** - So the opposite of that, when they are asking for treatment that you and the doctor may not give in that circumstance, can you talk me through that?

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**Ms McKENNA** - It is a different situation. In the first situation, if we went against their expressed wishes, it is essentially battery in many ways because we would be doing something to someone and who said they didn't want it done. It is a different situation where a patient may be, if you like, requesting, demanding or insisting upon a particular treatment. If that treatment would be clearly futile, clearly not going to benefit them, or perhaps even going to cause them harm even though they are unable to understand that at the time, then a doctor is under no obligation to provide that treatment.

**CHAIR** - But if that treatment was to end their life?

**Ms McKENNA** - If they are requesting me to do something to end their life the doctor is under no obligation; in fact it would be illegal to do so.

**CHAIR** - So it is very clear?

**Ms McKENNA** - Yes, and I think medicos have in their minds the difference between meeting the demands of someone and actively doing something.

**CHAIR** - There is no grey space there?

**Ms McKENNA** - If they are specifically requesting euthanasia - I think that was the question - there is no grey space there, no.

**CHAIR** - That's helpful, thank you.

**Mr JAENSCH** - I want to go to a term in your submission where you are quoting from the European association - 'intolerable distress'. It is quite a subjective thing - 'intolerable', we expect, to the patient.

**Ms McKENNA** - Yes.

**Mr JAENSCH** - So we are projecting into their head. The forms of response to that are something short of lethal but are designed to relieve and may have a secondary effect of hastening death. I expect these are not reversible treatments. You talk about continuous deep sedation.

**Ms McKENNA** - It is difficult because people use the term differently. Where I have referred to continuous deep sedation there, we are talking very much about the ultimate end of life, although I would say in some countries that is introduced well before that phase and that is where the controversy lies.

**Mr JAENSCH** - Is there any guidance or light you can shine on what that trigger of intolerability is? We have heard, and will hear more I am sure, about other states and the degree of what is intolerable suffering.

**Ms McKENNA** - I have had some experience working in palliative care - not a lot, six months as a registrar here and there. On a handful of occasions I have seen people who haven't necessarily been in uncontrollable pain or with uncontrollable systems, but are in deep existential distress, but they have been able to participate in the decision making so that has made it somewhat easier. They have decided they would rather be a little bit less aware of what was happening than be fully aware to try to manage that.

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You will hear from other people, I am sure, that with so many things in palliative care, very rarely there is a sudden decision to do something. It is little steps so often, and that is what I like about the way the European association talks about sedation. Sometimes sedation is used for a very short period and it is a light sedation. It is now something we can titrate very well to help someone get over a hurdle and give them some relief. People might say, 'I just need some time out'. In terms of those anxieties, existential fears and concerns, that is often how sedation might be used. There are those rare circumstances where someone says, 'I don't want to and I haven't got it within me to go through this anymore'. They are very rare and there are also some catastrophic symptoms, some we know are truly unpleasant to experience as you die.

**Mr JAENSCH** - Fluid and the drowning thing we hear about?

**Ms McKENNA** - Massive haemorrhages and things like that. The palliative care clinicians that I have worked with, if people want to know how they may die - and most people do, in my experience - they will often talk through possible things. 'We can never be sure, but this could happen and in the event of that happening, would you like to be less aware of what was happening?' That is an instance of deep sedation. The focus is on the patient, on the relief of their symptoms and stress. Yes, it may hasten their death but that is not our intention - and it would be seen as appropriate.

**Mr JAENSCH** - In that regard, could you contemplate a situation where someone had an advanced care plan which set out the circumstances under which their wish would be that they be given continuous deep sedation?

**Ms McKENNA** - I can, and I think I might know where you are going. I believe that under some circumstances, from our tradition, that could be an expression that they are requesting assisted suicide or euthanasia. If their intention is to have continuous deep sedation initiated early with the intention of deliberately shortening their life, they could -

**Mr JAENSCH** - Not necessarily, but under certain circumstances.

**Ms McKENNA** - It could be an expression of a suicidal -

**Mr JAENSCH** - Once we have established this continuous deep sedation - non-reversible, terminal - you have given us an example of where the patient has been able to participate in that decision. On the other hand, we have a doctor making a decision without an informed patient because they are not in a state to provide informed consent and we have an advanced care plan here. There is grey there and it is necessarily grey, I think, but it is an area that maybe gives some answers in that for people.

**Ms OGILVIE** - My question is on a very similar line.

**CHAIR** - Would you like Brigid to respond to that?

**Mr JAENSCH** - I am not sure Brigid can go any further with that and I don't want to push it.

**Ms McKENNA** - That is okay; I want to clarify that. I acknowledge a patient could request and a doctor could initiate continuous deep sedation with euthanasia in mind. We talked about the intention that we have to go back to what people are requesting and choosing to do. I would

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suggest to you that perhaps, not in Australia but in some other countries, continuous deep sedation is used as a method of euthanasia. That is why I was very keen to put in and make reference to the European Association for Palliative Care. They deal with continuous deep sedation in depth and clarify the different way it can be administered. There is a depth to their discussion which is important if we are going to be honest about what people might be requesting and what doctors might be administering.

**Ms OGILVIE** - I know we have not touched on this topic but it is closest to my heart in this area, and it is neonatal and paediatric palliative care, and the complexity of decision making around all those things which is a little bit similar because it is a question of competence. It seems to me that a lot of thinking has been done in medical ethics and Catholic teaching around the decision maker for the child and who that is. Do you have particular comment around that perhaps in complex decisions, perhaps where we have a vitalist medical professional and you have a parent who is ready to - how do you manage through those situations?

**Ms McKENNA** - I have never worked in that area, however, about 10 years ago I was at a meeting of a whole range of health care providers, but where there were a lot of Catholic health care providers and ethicists from the church where people really got together and said this is actually something we are doing very poorly in Australia.

**Ms OGILVIE** - Good. I mean not that you are doing it poorly but good that you are talking about it.

**Ms McKENNA** - There has been quite a development since that time. I mentioned in the submission that Catholic Health Australia now has a website, and that it is trying to engage in some research and so really trying to deal with such a complex area not only for the reasons, Ms Ogilvie, that you mention but also because so many people are involved.

**Ms OGILVIE** - Absolutely, and the time frame is compressed as well so it can go very quickly wrong, if it goes badly wrong.

**Ms McKENNA** - It is, yes. I think it is an incredibly specialised area of palliative care that needs its own focus. Difficult, I suppose, because we are talking about not that many numbers, thankfully, and I suppose that is what has held it back, but also the fragmentation of care has been something. There are moves afoot now in Australia to follow some overseas models where we start to really - it is the true multidisciplinary approach because we have people involved in antenatal care, we have intensivists. It just goes on and on.

**CHAIR** - Brigid, thank you very much. It was really interesting.

**THE WITNESS WITHDREW.**

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**Professor BEN CANNY**, FACULTY OF HEALTH, UNIVERSITY OF TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

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

**Prof. CANNY** - I am appearing here on behalf of the Faculty of Health, University of Tasmania, and my role there is head of the School of Medicine, which incorporates disciplines of medicine, para-medicine, pharmacy and psychology, but the whole of the faculty also includes a range of other disciplines, including, importantly, that of nursing. So I am here on behalf of the faculty.

The faculty appreciated the opportunity of making a submission to this enquiry because we see a number of roles for the faculty. Primary among them is the training of the next generation of health care providers for Tasmania, but also providing the research or evidentiary basis on which good health care is delivered and also an important public community function.

Our interest in this enquiry is to engage in that area of what is the appropriate education? How do we get the appropriate expertise to inform that education and to inform both the health care and the research into health care in Tasmania? Then the communities spread from that point.

In the submission, I will not go over it specifically now, you can see the faculty is actively involved in a range of educational activities. We also have a Professor of Palliative Care in Professor Michael Ashby. He has shared his submission with us, and Michael also does research in this area within his role with the university. I am happy to answer any questions.

**Ms DAWKINS** - There was discussion yesterday about the lack of death literacy. In general, with medical professionals - throughout our whole community we have removed ourselves so far from death - there is an idea that GPs are missing that first opportunity to - the continuum of health care which is going to end up with death, the appropriate time to talk to someone about that so we can have advance care directives, all of the legal and ethical framework around that. Perhaps we are missing that fantastic opportunity to start that with our GPs. What do you think about that?

**Prof. CANNY** - I think that there is good evidence to suggest that what you are contending is appropriate and accurate, and it is a mature society that can talk about death in a sophisticated way and I suppose all societies are aspiring to be mature. I'm not saying we are being immature, but it is an important way of developing.

I think that provides a distinctive opportunity for the university in several ways. One is if we are thinking about general practitioners, they need to be medical graduates to start with, so we

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have quite a bit of exposure to palliative care in the undergraduate curriculum. We also have strong relationships with places like Primary Health Tasmania and so forth, and the rural and generalist pathways and things along those lines. In fact some staff get shared between the two institutions, sometimes by conjoint appointments, but others by dual appointments, so I think there is a great opportunity for the expertise we possess to be shared more broadly to help with that education.

There are two things we need to do. One is making sure the next generation has the capacity to do things that are important and empowering them to be agents of change. I have seen in my career in medical education lots of instances where the juniors can bring about change, but at the same time recognise you have to do some big things to change cultures and to make people more familiar with it.

I was at the health forum the minister held last night; perhaps some of you were there but I kept my head down a bit. It was intriguing that a number of things people spoke about were instances associated with death. One of the things we are missing a bit in our health care systems - and I think this occurs everywhere - is a focus on who is the conductor of the orchestra of the patient's journey of care. I think GPs play an important role there, especially in a state like Tasmania where there are geographical and financial imperatives or considerations about whether other health professionals can also be involved in the orchestration of that care.

**CHAIR** - What other health professionals would you consider?

**Prof. CANNY** - Probably the most appropriate is the nursing profession and I think there are two areas within that. One is the nurse practitioner who has more advanced training and is used to working with people in making decisions, and the other is community health nursing.

**Ms OGILVIE** - Like district nurses, those people?

**Prof. CANNY** - Like district nursing, but there are a number of models of outreach care. District nursing is one model and that is all I mean by that comment. I think there is an opportunity for that role substitution to be carefully thought about.

**CHAIR** - What about the people who do not go into traditional, normal medicine? I do not know how to express that appropriately.

**Prof. CANNY** - 'Alternative' is sometimes the word that is used.

**CHAIR** - Yes. What about those professionals, should there be training for them in this area so they can be part of this, or do you think that is a risky area?

**Mr JAENSCH** - You are talking to the Head of Medicine.

*Laughter.*

**CHAIR** - I am playing devil's advocate.

**Prof. CANNY** - It is a great thing to play devil's advocate about because we know that out-of-pocket expenses for alternative medical care in Australia is much greater than it is for traditional care. That is the traditional approach. I think Madeleine got it right. In my role and

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with my training, I am going to be primarily interested in those professions which are regulated and for which there is an evidence base for their practice. This is an argument I have had in my home. That being said, I recognise that for some of the alternative areas of practice, gathering the evidence is more complex than it is for traditional medicine and that is a combination of traditions of gathering evidence and philosophies but also the fact that you might not have Big Pharma behind it or the NHMRC or whatever - things along those lines.

Coming back to Andrea's comment, I think a broader death literacy in our society is critically important. For people who administer care to individuals, it would be useful for them also to have a degree of literacy about death, a greater knowledge about knowing when they are out of their depth and when to refer and things along those lines.

We are all aware of two things. Firstly, the stories where people gain benefit from those interactions where they don't from traditional interactions, and there are all sorts of complex reasons to that, some of which should fall squarely in the lap of traditional practitioners and their lack of ability to communicate and be patient-centred; and we are also aware of other disastrous situations where there has been persistence in therapy which is unfounded in science and has led to someone's earlier demise.

I won't sit on the fence. I think that our primary focus should be on the regulated professions, however, we as a society should increase our health literacy and provide an environment where there is greater permission for people to recognise when they are out of their position of comfort and move things on.

**CHAIR** - You haven't included the clergy in your list. Did you intend that?

**Prof. CANNY** - No, I didn't intend that specifically. I was thinking more about homeopaths and the like. I don't think of clergy as part of the health system and perhaps that is my problem.

**CHAIR** - But in terms of dealing with death - to Andrea's question - death is not just a medical matter.

**Prof. CANNY** - Yes, and we could add lawyers to that.

**Ms OGILVIE** - And accountants because of complex situations.

**Prof. CANNY** - Yes, absolutely.

**CHAIR** - It is about the conductor of the orchestra, to use your words.

**Prof. CANNY** - Yes, but I've forgotten about the woodwinds, haven't I?

*Laughter.*

**Ms OGILVIE** - As a preamble, I was very fortunate to get a bit of funding to look at some other jurisdictions and it was hard to choose what to see but I went to the Levensindekliniek in the Hague, which was an end-of-life centre, and looked at the Dutch legal regime around that. I also went to Kings College, London, and spoke to the lawyers on the medical ethics because the English had just been through a lot of these conversations. I also spent time in Ireland which, as you can imagine, thinks itself very good at death literacy with lots of wakes and drinking and all

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of those things, which they say is to do with the fact that they don't have a lot of money so they do it at home. That sort of resonated with me.

**Mr JAENSCH** - Deep continuous sedation.

**Ms OGILVIE** - Self-inflicted deep continuous sedation. I came away from that experience with a refreshed view of the diversity and complexity of the world and humanity and all those things, but one of the things that struck me that the Irish were doing well at the University College in Dublin was the establishment of their Institute of Palliative Care, which was a five-year funding agreement which enabled them - almost like a CRC - to put together a multidisciplinary show around that, which is where your lawyers and accounts and allied health professionals come into play. If we were going to put an orchestra together and plan for that, is that something that could be considered? Is that something that the Faculty of Medicine - if I brought you heaps of funding - wouldn't say no to? Is that something that might progress?

**Prof. CANNY** - The answer to your question is yes, because such enterprises are critically dependent on the quality of individuals you can inject into the situation. If I look at the strengths in Tasmania, there is a significant degree of strength with regard to palliative care. Michael Ashby is a noted international leader, but there is also great academic strength in the area of law, which I notice Margaret Otlowski is giving in the submission. I have already sought some medico-legal opinions since my time down here from members of the Law Faculty. I would think definitely, yes. The critical thing that I am not certain about is the conversation which would frame what would be the function of that particular unit. I am relatively new to the state so I am getting to grips as to where the challenges lie, but I do know several things about Tasmania - one is that it is an older state than the rest of Australia. I also know that the health outcomes are not quite as good as anyone would hope and there multiple factorial aspects to that.

Further, there is an interesting dispersal of the population that when you come from the 'big island', is surprising. The geography is quite challenging. We should focus on the proper organisation of the distributed care plans across the state, intertwined with some of the medico-legal issues. It would be a very interesting thing.

The spiritual side of life could be added to that. How do we prepare for passing on things to our next generation and so forth?

**Ms OGILVIE** - The university college, it seems to me, was doing that quite well - bringing in those different specialisations. We have the Law Reform Institute but to have something that was focused on what I think of as one of our greatest medical challenges, because of the inverted pyramid of our demographics, and this need to improve increased death literacy and how we would communicate that and fund that - Who would take the leading role in identifying those things?

**Prof. CANNY** - A couple of additional comments. Fifteen months ago it would have been easier to say that the university is uniquely placed in being a trans-state organisation. I think it remains very well placed but I think the THS provides a really interesting opportunity with a single THS also. Relationships between the faculty and the university are strong. They would also be an absolutely critical player in this. There are all sorts of things to consider. In a distributed plan, how do you get the services out there? And who is doing the services? It is an interesting question. Would you have a palliative care doctor in Strahan? Probably not, but would it not be good to have somebody who had some skills on the west coast? It does not

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necessarily need to be a doctor because doctors are difficult to train and as well as being expensive to train.

**CHAIR** - Yes, the conductor of the orchestra.

**Prof. CANNY** - Yes. In health, often it is a medical practitioner, but does not need to be.

**Mr JAENSCH** - Briefly, Ben, there is a theme emerging around this culture of dealing with death in using our medical professions and the rest of the orchestra. We are going to have to try to influence training your medical students, and then there is other slightly hazy area, to me - these colleges they are admitted to, which are the holders of traditions and the areas of ethics and practice. It is one thing to teach it but I believe though that the centre of the culture is held among these Jedi people. How do we influence that? Is that a correct perception? It is germane to this challenge that we have regarding a culture of talking about death?

**Prof. CANNY** - It is even deliberately named. It is called the hidden curriculum and these are a variety of things. It refers generally to the cultural and ingrained attitudes and beliefs which can sometimes completely defeat the best intentions of those who know or educate.

It is the same sort of hidden curriculum and culture that has unfortunately led to the hegemony of the medical profession. It has led to some of the cultures of bullying and so forth that we read about. So I think the time is right for, some action to bring about some changes because a lot of work has been done. The Royal Colleges are where you go to be a specialist. Ironically, often people who are specialists end up are appointed at universities but we don't make it an environment for them - for the two sides of their brains to talk well together. Often they have quite separate identities. However, we have this general attitude within the medical and health care profession that there is a whole bunch of cultural things that are not appropriate. It is time to face them up front and change them. The other thing is that the colleges have also, more recently - over the last 10 years or so - been subject to the same accreditation requirements that the universities are. They are accredited by the Australian Medical Council and it has driven them to have explicit curricula - as well as that hidden curriculum I was talking about before - and those explicit curricula actually deal with things like ethics.

The College of Anaesthetists has a chap who deals with palliative care, so they have got a direct interest there. The College of Physicians has a chap who deals with aged care. If you want to get into an argument, speak to a gerontologist as though they are a palliative-care doctor, but there is a significant overlap. I think you have to tackle these big cultural change issues from multiple directions.

**Mr JAENSCH** - That also means that we can't deal with them comprehensively, only for Tasmania, because the colleges are above that.

**Prof. CANNY** - Yes, the colleges are national colleges, although they are all organised on state lines. They will have a state chapter of the College of Physicians. You are right, but you have got to start somewhere.

**Mr JAENSCH** - Can a parliament say to the College of Physicians, the people need you to be talking with them and dealing better with this area of death. We need someone there. You can't just step out of the room at the end of what you think is your job. How do you address something like the college?

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**Prof. CANNY** - Parliament certainly can say that. Whether they will be listened to is probably your real question and I don't know. I am not a fellow of a college so I don't have a deep understanding of their constitutions and how they are organised. Tasmania has representatives on the Australian Medical Council and representatives on the Medical Board of Australia. So if one looks at the governance, the Australian Medical Council is an independent accrediting body that makes recommendations to the Medical Board of Australia about whether particular courses or areas of training will be accredited. If they are accredited, the products of those training courses will get registration rights and responsibilities, so there is quite a lot of power in that. The Medical Board of Australia has a chapter in Tasmania with specific Tasmanian representatives on it, so perhaps the influence of the Parliament is more via that quango rather than via direct link to the colleges. The Parliament certainly has an ability because universities fall under an act of the Parliament of Tasmania, so without knowing all of the governance I would be looking where the governance lies for further ways to intervene. The final thing is that the THS is the employer of many of these individuals so -

**Mr JAENSCH** - I don't think that is the way the people employed see it.

**Prof. CANNY** - The CSO has suggested it might be the employer and you probably heard that as well. Again, while you do not want to use industrial sticks, you have to say an organisation is responsible for its culture and most of what we are talking about here, Roger, are cultural issues.

**Ms OGILVIE** - You mentioned all the different groups that sit under your leadership such as nursing, medicine, para and all of those. Do they all receive palliative care training or death and dying training in their core curriculum?

**Prof. CANNY** - The simple answer is no.

**Ms OGILVIE** - Can you fix that?

**Prof. CANNY** - I train some laboratory scientists so I will not fix it for them but I do know that medicine and nursing receive significant training and there is some in pharmacy. We're bringing para medicine along to think about death and there would be some classes on death for those training to be clinical psychologists.

**Ms OGILVIE** - So the answer is pretty much yes.

**Prof. CANNY** - Pretty much, but I could take that as a question on notice.

**Ms OGILVIE** - That would be great.

**Prof. CANNY** - If you want to say what is the coverage of those most obvious places, it is good and extensive.

**CHAIR** - My question is in regard to continuing professional development. I am not a medical person, so what is the role of the university in continuing professional development for existing medicos? We have heard evidence that there is a gap. How does their CPD work? Who funds it and where does it come from?

## **PUBLIC**

**Prof. CANNY** - I will deal with the role first and then talk about the funding. There are three questions there: role, opportunity and what is actually happening. The university does not have a formal role with regard to CPD. Individuals need to undertake appropriate CPD to maintain their practice and much of that is defined by either the boards that register them or the colleges that maintain their qualifications and so forth, so if you are member of the College of Physicians, they will have extensive definition of what appropriate CPD is. The GPs are the same, and so forth.

We are involved in developing a range of short courses and the like, some of which can be used for CPD. I do not believe there is any in the area of palliative care at the moment though there are a number within my school at the moment who are talking about developing units around the issue of death and dying, mainly targeted at community training, a bit like the dementia link and things along those lines, accessing that. The final thing is that I think there is an incredible opportunity -

**CHAIR** - For the university?

**Prof. CANNY** - Yes. Tasmania's size and the inter-connectedness of the individuals, if that makes any sense, does provide an opportunity.

**CHAIR** - Thank you very much.

**THE WITNESS WITHDREW.**

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**Professor MARGARET OTLOWSKI**, UNIVERSITY OF TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

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

**Prof. OTLOWSKI** - I will elaborate a little on what I put in my written submission. My starting point would be: what is the genesis, in a sense, for this inquiry to acknowledge that there are often problems in practice that the care of people at end of life is often not optimal. This can take the form of unnecessary or excessive treatments. It can also take the form of lack of appropriate palliation.

It is well documented that end of life is not done well in Australia, and that is the case elsewhere. I did make reference to an article that reported on international data. I think we still have a prevailing culture of doing what is possible. So the capacity to keep people alive often leads to almost a responsibility to do things even though they are not going to improve the quality of the patient's life let alone cure the patient. So we would all agree that interventions need to be ethically and clinically appropriate and aimed at actually improving the quality of care at the end of life. The studies that have been done on the problems of care point to a number of difficulties which I think are quite illuminating. Sometimes it is family pressure on the health professionals; sometimes it is breakdown in communication; sometimes it is medico-legal concerns, and that is an underpinning of some of the other points I would like to make.

Clearly this is difficult terrain. There are some points where there will be strong differences of view, particularly if you start talking about direct assistance at the end of life, but I think there is a lot of ground on which there could be considerable consensus in this area. I briefly want to draw attention to two or three areas where I think there is real scope for reform; this is evident even from what is already around Australia. There were things in Madeleine's bill.

One area I would like to highlight is that of administration of pain relief, which we know may, in some circumstances, have the effect of shortening life. Even though this is assumed to be a legal and accepted practice in Australia, if you actually go to look for the legal basis of it, it is very thin, in fact you find the contrary. So we rely on a common law principle derived from a House of Lords case - Adams case - the summing up to a jury which indicated as long as you are not intending to hasten death; that your purpose is to relieve pain and suffering, it is a distinction that is drawn between intending and merely foreseeing death. You are not allowed to intend it but if you merely foresee it with the purpose of relieving suffering, that is okay. Yet, if you try to align this with the requirements of the Criminal Code, this is the real challenge. Obviously it covers intentional killing, but it also covers killing knowing where it is likely or probable. So there is a complete disconnect and this will be the subject of recent evidence from my colleague, Dr Jeremy Pritchard, which I know you have discussed with him.

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**Ms OGILVIE** - It has been raised earlier as well with Mr Godfrey.

**Prof. OTLOWSKI** - With that background, it is no wonder, particularly in a code state where I think it is problematic, because unlike common law Australian jurisdictions which can evolve, with a code it is the interpretation of the code that matters.

There is consequently an environment of legal uncertainty which will lead some doctors to practise defensive medicine if they are concerned about their liability, or if they are fear others will perceive what they are doing as overstepping the mark or approaching that kind of zone of more direct assistance.

I think we would all agree that we want people to be relieved of the suffering or symptoms of suffering and that doctors should be able to administer with confidence pain relief as medically indicated. I would urge strong consideration of creating that clear legal exception in the same way that the South Australian act has done and that was mirrored in the bill that has been put forward that covers things such as doctors acting in good faith; acting in accordance with proper professional standards, including you could specify palliative care, that it is with the right intention, that is the intention of relieving pain and distress, even if it may have the effect of hastening death.

We have the example in South Australia. Notably other code states - Tasmania is a criminal code state - such as Western Australia and Queensland have amended their codes. In our state, with the code as it is, this is left wide open as a troublesome area. No-one is talking about prosecuting doctors, but they are being exposed to potential liability so I think that should be addressed.

I note that the Victorian enquiry into end-of-life choices - I am sure you are familiar with the great wad of material and recommendations - had talked about continuous palliative sedation as something that could be part of appropriate end-of-life care, and made some recommendations around that including giving legislative effect to this double-effect principle. I think the fact that we have legislation in some states, others are looking at it, and particularly given the disconnect with our code and assumptions about this being lawful, there is not clear case law authority in Australia, although I did find one case in the family court jurisdiction where they had clearly articulated support for the double-effect principle, but that is not a criminal law case.

**Mr JAENSCH** - Does that not then become intent for the second effect if you acknowledge it?

**Prof. OTLOWSKI** - It was because it is in the Family Court jurisdiction as to whether the parents could give permission for a tube to be removed even though they knew the child would die, and asking doctors to be able to alleviate what they knew would be the pain of asphyxiation. The court acknowledged that that was going to be appropriate, so effectively we have a judicial precedent but it does not really deal with criminal liability because it was more to do with parents and the scope of authority -

**CHAIR** - To cease treatment.

**Prof. OTLOWSKI** - Yes. I think the other big area relates to the withdrawal of treatment which can take the form of not doing something but also sometimes involves turning something

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off, so it can be acts or omissions which effectively constitute a withdrawal. I think here too there is a lot of ambiguity about what rights patients have to direct that nothing further be done or what the responsibilities of doctors are and the scope of those responsibilities to administer treatment, so I think we could benefit from clarity of these rights and obligations in the same way through clear legislative statements. That has been done in the South Australian bill and the Victorian inquiry also acknowledged the degree of uncertainty around this. This also would benefit from giving statutory effect to what really is common law understanding about a patient's rights to refuse treatment and doctors not having to administer treatments that are futile and so on.

I think they are for me probably the main areas of focus. What I mentioned in passing in my submission is that I am on the record for supporting more active assistance at the end of life. I know that is not directly within the remit, given the terms of reference, but I would note that for me it was interesting to see the Victorian inquiry embrace the thinking of some legislative scheme that would allow doctors to administer drugs to a patient that could be self-administered. That is more an assisted suicide model unless a patient physically can't self-administer, in which case perhaps more active treatment would be required. It seems to me that progressively we are moving in a direction where in time perhaps we as a country are able to contemplate such measures, but given the terms of reference perhaps we can focus on the other areas where I think there is perhaps more agreement.

**Mr JAENSCH** - I won't go back to the clarification of the laws regarding administration of pain-relieving drugs - I think you have covered that well in your overview. On the first page you make reference to legislative provision for advance care directives and I am interested to know in what dimensions you thought that provision could be made and whether it touches on the idea of having some method of formal registration of binding directives for informed consent. What are the most important aspects that need statutory support?

**Prof. OTLOWSKI** - We need to ensure that the autonomy of patients continues beyond the period of their competence. We need a regime that is well documented, where there is clarity about the sorts of things they want to describe in terms of the treatments they do or don't want, and that is formalised so there can be a process of registration. If you don't have it documented and registered and there is a go-to place to check what is on the record for a person, it will be hit and miss as to whether - if a person is taken by ambulance - it is known if they have put their wishes in writing and how to access it. We really need to use the electronic health records system to ensure ready access to a patient's statement.

**Mr JAENSCH** - Multiple providers won't be able to access that where it is relevant.

**Prof. OTLOWSKI** - Yes. You touched on the issue of informed consent and I think a key part of what is going to be needed is an educational push to enable people to understand the importance of thinking ahead to end-of-life issues, in the same way people are encouraged to think about whether they want to be organ donors. It can all be part and parcel of that so there is clear information about the sorts of things that can arise and how they can make informed choices. There are precedents; some states have introduced this through legislation or other means. In Tasmania you can probably put something in writing but it is not 100 per cent clear what force it has. I support some advance directive or care plan model that has formality.

**Mr JAENSCH** - In doing that, if there is a central registration of an appropriately-worded and consented or otherwise disciplined plan in there - I am thinking about legal and privacy matters here - to me that also comprises a database. It is a very important instrument, particularly

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when it comes to future decision-making about what the state provides as options for dying. If we have a series of things that are declarations about what a person wants, it is something we can compare against what the state provides. We are hearing in this inquiry from people who will quote to us the statistics about demand for and attitudes to voluntary assisted dying and other matters, but it is usually not from dying people, it is from the general population. If we registered care plans that had some rigour to them, would we sensibly build in some sort of capacity for those de-identified, but for that to be an information base for making policy?

**Prof. OTLOWSKI** - I totally agree it could be a useful resource. It is not necessarily the voice of people who are dying because often these are done when people are robust and in full health. The same conscientious people who think about making a will might make these, but on the other hand, it is a good indication of what people would optimally like in the future for themselves. As someone who comes from a university setting, the idea of thinking in advance about the research opportunities to look at what the majority of people say and then to use that as an evidence base to ensure fitness for purpose in the health system is a good one. I can see the synergy. Whether that means we should include in the form some indication that that would be one of the purposes - I think people would be pleased to know not only is this going to be recording what their wishes are but that there is a broader interest in this state to use this information in a de-identified way to help inform its health policy.

**Mr JAENSCH** - As distinct from the census, which everyone is scared of all of a sudden.

**Ms DAWKINS** - Do you think it would be possible for us as a community to talk about a legal framework for advance care directives without talking about voluntary assisted dying, if we have to go through one step to get to the next step? Do you think that is something logical we could do?

**Prof. OTLOWSKI** - I think we can talk about the whole 'do not resuscitate' thing and the different phases may find themselves in and what they would want to happen in those sorts of circumstances. It can then alleviate the responsibility of loved ones who would otherwise have to make decisions if the person has not voiced their choices themselves. If there was a will to look at a more direct assisted dying - although I have to say I am not on the record for combining advanced directives and assisted dying. To take the step of directly assisting a patient needs considerable safeguards and one of them is active competence to ensure it is and remains the person's wish. It is dangerous territory to be thinking you can do that in advance so I think it is better they are not combined.

**Ms OGILVIE** - In a similar vein, you are aware of my views about people practising unnecessary defensive medicine and I, too, think that the human driver behind that is the fear of doing the wrong thing, so they do too much, which is the genesis of this conversation. I was really pleased with Andrea's question because I, too, think we can do a lot more with what we currently have. I have been talking with Jeremy Pritchard about amendments to the Criminal Code and I believe there is grey area there.

**Prof. OTLOWSKI** - I think there is real need for looking at that.

**Ms OGILVIE** - Indeed. That is something that is probably not the subject of this inquiry, but I do think it needs to be addressed. That is something we might seek assistance with.

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**Prof. OTLOWSKI** - Indeed. I checked in with Jeremy. I wasn't sure if he was going to be giving evidence and if we would be back-to-back, so taxiing in I did check in with him. He had the materials out on his desk and he will be trying to give a succinct but clear account of the criminal law position in this state vis-a-vis double effect and the implications on palliating people's pain where that might have the effect of hastening death and how that sits. In fact, he did ask me to indicate that is definitely forthcoming. He hopes that it may be something that we can submit jointly if that works that would be great.

**CHAIR** - Will we be able to accept a late submission?

**Ms OGILVIE** - On that topic, I am on the record for not being able to do the whole euthanasia thing.

**Prof. OTLOWSKI** - I totally respect.

**Ms OGILVIE** - Experience, as you understand, but I think there is so much more we can do in the current space. We heard some evidence yesterday around palliative care leading into euthanasia being a continuum. I was fortunate enough to go and visit different jurisdictions. I went to the Levensindekliniek, The Hague, and I looked at how they managed their end-of-life euthanasia program. I had a very good conversation with the two women who were in charge of it. They went to great pains to sketch for me the parallel but separate areas of service. What they do on the euthanasia side has a separate board, separate funding, separate staff and on the palliation side, it is the different model. To my mind, I am not sure the two things are necessarily connected, although I appreciate the conversations bring on the one and the other. Do you have any views around that?

**Prof. OTLOWSKI** - I think you are correct. I think that the Netherlands is an interesting model because often, it has been suggested, they do euthanasia and therefore they must be poor in palliative care, but they are actually exceptional in their palliative care. The choice of euthanasia is for a small minority. Even if you had a lawful space for it, single figures will seek that option and yet there are many more people who need palliative care. I think the Netherlands is a model to show that you can have this option -

**Ms OGILVIE** - One does not replace the other.

**Prof. OTLOWSKI** - I think I would be worried if it was an example of active euthanasia, but really shabby in palliation, because that would then suggest that people are seeking that because of lack of appropriate treatment. I can understand why, for some people, it seems like a continuum, particularly if you use terminology such as 'terminal sedation' or 'pharmacological living'. I think the Victorian committee uses the word 'continuous palliative sedation'. It does beg the question: Is this just a slow form of euthanasia? There are arguments you can make to say there are similarities, but I think we can accept that there a difference, also for the health professional in something that is -

**Ms OGILVIE** - It's a mens rea issue, isn't it?

**Prof. OTLOWSKI** - Yes. Also it is something that very actively and immediately has an effect and something, which is for a different purpose and has a slower effect. The circumstances where you know the patient is not going to regain consciousness and you are keeping them comfortable with a bit of mouth care and so on - effectively we know they will die and what is

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being done is facilitating that. But I think we have to be brave and find a way to accept that that can be part of the medical practice, because what is the alternative? The alternative is unbearable suffering. So we need to be able to carve out the legal exceptions with enough clarity to allow appropriate palliation at end of life so that people don't fear, firstly, that it is going to be alleged to be euthanasia and that there is not a holding back of measures that are necessary for the relief of pain at the end of life.

**CHAIR** - Does our Criminal Code, whether it is state or federal - however that works in the criminal sphere - have a right to die within it?

**Prof. OTLOWSKI** - No, I don't think it does. No. We sometimes look to: Is there a right to life and is there a corresponding right? I think everything in the code speaks of protecting life. Some would therefore interpret that as saying so therefore we can't do anything that impinges on life or takes life early. But I think the arena we are in, we have to be able to, if necessary, carve out and identify the exception, for example, for palliative care and so on. So there is no right.

In terms of patients being given the right to demand things - there has been discussion should there be a bill of rights in Tasmania. One of my colleagues led the reference of the Tasmanian Law Reform Institute on that and there is much to be said for a broader bill of rights. But I think we can deal with this area effectively without creating 'rights to die' as such and they are certainly not there at the moment, as I understand it.

**CHAIR** - How does 'refusal of treatment' and 'lack of right to die' fit in?

**Prof. OTLOWSKI** - It is an interesting one in that the refusal of treatment rests on the autonomy a person has and the control they have over their body, and that they cannot be compelled to have things done to their body that they do not consent to. So that means you can reject anything, including nutrition and hydration, if you are a competent person but that freedom of autonomy does not allow you to empower someone else to actively do something to assist you. Even if they are consenting, you can't give legal authority for someone to give active assistance, so it is all to do with rejecting. The authority or the autonomy of an individual doesn't allow permission to have active assistance. So that is why there is no 'right to die' in the sense of active assistance. But, if you think of it in terms of the passive, there is a right to refuse treatment and that in turn can lead you to die. So, in that sense, even though it is not stated as a 'right to die' in the Criminal Code, there is nothing in the Criminal Code I think that would require doctors to continue with futile treatment.

**CHAIR** - I am thinking about the provision of the necessities of life. There is no interplay between that part of the grey area for -

**Prof. OTLOWSKI** - That is an interesting one and this is where Jeremy needs - but I would be flabbergasted if a criminal court, judges interpreting the criminal law would interpret that as imposing an obligation on doctors in ridiculous circumstances of an extraordinary provision.

**Ms OGILVIE** - And it has never been used like that?

**Prof. OTLOWSKI** - No, it hasn't but it is probably something we could get him to perhaps touch on.

**CHAIR** - We sincerely thank you for your time.

**PUBLIC**

**Prof. OTLOWSKI** - Very happy to assist.

**THE WITNESS WITHDREW.**

## **PUBLIC**

**Mr PAUL RUSSELL**, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED BY TELEPHONE.

**CHAIR** - Welcome. 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 the fear of being sued or questioned in any place or court out of parliament. It applies to ensure that parliament receive the very best information when conducting its inquiry. It is important to be aware that the 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 proceeding. This is a public hearing, so members or the public and journalists may be present and this means that your evidence may be reported. It is important that should you wish all or part of your evidence to be heard in private, you must make this request and give an explanation prior to giving the relevant evidence.

**Mr RUSSELL** - I want to open with simple observations about the term 'wellness'. Wellness is generally used to mean a healthy balance of mind, body and spirit that results in an overall feeling of wellbeing. I think when we talk about public health, we usually about our system of GPs, specialists, hospitals, hospices et cetera, and not so much necessarily about wellness. I want suggest that wellness very much includes public confidence in the system; confidence that should any medical need arise that a person will be treated well, in a timely fashion by a professional so they can rely on good assessments of the facilities that can be relied upon for good care.

As I observed in my submission, I think there is a need to 'sell the story' of palliative care to explode the myths and thereby to increase public confidence and therefore a sense of wellness in the community. Of course that story needs to be backed up by reality. Inasmuch as all Tasmanians have access to the very best of end-of-life care, then it is a good story. Inasmuch as Tasmanian GPs are confident that they understand palliation and have used the techniques and how to refer a patient in a timely fashion to appropriate care service. Then, likewise, this contributes to confidence and wellness.

I speak often to palliative care specialists. They can sometimes be very critical of the lack of knowledge and lack of consultation in some of their colleagues that sometimes leads to a less than optimum outcome for people.

There was a time, I was told, when palliative medicine was something of a novelty that was perhaps greeted with some suspicion or derision, even in specialist medicine, almost as though to refer someone to palliative care was taken to be admitting defeat. It was a conflict, perhaps, between the ego of the specialist and the best interests of the patients or, perhaps, simply because there was that chronic lack of understanding of the benefits that palliation could deliver over and above the skills of a particular treating physician. I think that time has passed, or is certainly passing, but I also think that there is more that can and needs to be done.

We observe too that the early cooperation between the GP or specialist and the palliative care team may also serve to streamline care, reducing duplication, worrying instances of emergency intervention, providing not only the possibility of home care for those who want it, but again an increasing sense of wellness as well as reducing costs.

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We argue that there needs to be some sort of inventory conducted, I believe, across Tasmania amongst medical personnel which seeks to identify gaps in knowledge and then to address these gaps through some form of training.

In our submission, I close by observing that we believe the Tasmanian Government's approach to palliative care needs to arise from a coherent vision that creates a sense of wellbeing for all Tasmanians, built upon a greater confidence, so their needs will always be met. It is about both provision and perception, I think. Both are roles that require cooperation between various members of government and the service providers and both, when done well, contribute to the sense of wellbeing.

I have also made some observations about advanced care planning and raised concerns about binding directives. Advanced care planning needs a context. It might be that people definitely want to talk with their own family members and come up with a set of desires and wants that they can express in a plan, even at a time when they are in good health and there is nothing pervading on the horizon. However these need to be met and interpreted and formulated in the context of care, whether that be with a consult with a GP, an aged care facility or retirement home in that first diagnosis or in planning for a procedure. The more we embed the review of such plans into a landscape of medical care, the more likely the patients wishes will be expressed properly and the less likely they are to be misinterpreted, both leading to better outcomes in care.

Sadly, to me the idea of a binding directive in terms of an advanced care plan is somewhat problematic. Certainly if the plan is refused, the likelihood of conflict between the direction and good medical practices is probably slim, but the problem I believe is deeper than that. I think there is a tendency these days to what I call a 'slot machine' approach to medical care, where the doctor is merely the provider of the service and the patient calls all the shots. It is a little like getting a candy bar from the dispensing machine, if you will allow me to make that kind of observation.

I think we must actively resist such developments in medicine because we know that the doctor-patient relationship is one built on conversations and trust. Decisions should as far as possible be patient-driven certainly, but they need to be appropriately subject to expertise and experience.

**Ms OGILVIE** - Paul, as you would anticipate, we have heard a lot from a lot of people and different views on the world but there has been some themes that have emerged which I would like to check in with you as to your views of the world. I hear what you are saying about getting the balance of rights between the patient and the doctor into balance. One of the submissions we had was from the director of the Office of Life, Marriage and Family in the Archdiocese of Hobart, and she talked intelligently about the doctrine of double-effect which seems to underline a lot of this stuff. Do you think you could, from your perspective, give us your view about that, because there seems to me to be some opaqueness in the community around whether we are palliating someone or engaging in something else. It would help if we could have a view from your perspective.

**Mr RUSSELL** - Yes, by all means. Let me first start by noting that the so-called doctrine of double-effect goes back to St Thomas Aquinas originally and that is a fairly long time ago, but in practical terms I am led to believe, particularly in a palliative care setting - and I heard this from an elder care specialist - that their ability to titrate drugs effectively for the patient's needs by virtue of their weight, experience and the degree of pain and suffering they may be experiencing

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is such now that the risk of that treatment accelerating death by any degree is minimal to the point of almost being non-existent in that setting, but certainly the principle is that it all comes down to intention. If the medical intention and the application of that intention is such that it is to relieve pain and suffering in a patient, even if there is a secondary known possibility that by doing so it may foreshorten their days, then it is an appropriate and ethical achievement if in fact the intention and the method is correct.

Some suggest it is a very much a grey area but I do not think it is, and certainly those I talk to do not think it is because they see that it has very little application in good palliative care, but also I think most doctors can understand what it is about intention and they certainly know the effect of the kinds of dosages given. Even though it is difficult in hindsight to look at intent and ask what the doctor intended, I think you can get an indication from that by the dosage and if the dosages are in fact significantly over and above what would be normal to expect to receive, then you may get into an area where you could question the intention.

**Ms OGILVIE** - Hypothetically, you may have a patient who the doctor knows has a terminal condition and perhaps in a palliative care setting offers deep sedation as an option which indeed has the effect of shortening life by a fair bit. How would you ever show that the intention was anything other than palliation if indeed there was a different intent such as pressure on beds and economic imperative. If there was a different mindset, how in practical terms would we ever discover that?

**Mr RUSSELL** - I am not sure that you can other than to reflect upon the dosages and the applications and the medical notes. I think if you had another doctor with similar or even greater expertise to review the file notes and he or she came back and said, 'I would have only given that person half of that dosage of opiates' or whatever, you might have cause to question either their expertise or their intention, but you are not necessarily ever going to know that formally.

**Ms OGILVIE** - So that seems to be a bit of a gap in the management process.

**Ms DAWKINS** - I would like to talk about the role of the enduring guardian and your concerns around loss of capacity with the advanced care plans, as you call them. If you are concerned that someone has lost their capacity and their directive or plan might not be appropriate for what has happened to them, could their guardian then step in on their behalf and speak to the doctor?

**Mr RUSSELL** - Well, it just depends on how it is written. If that particular point in their plan is in fact accepted as a binding directive then I think it would be more difficult to modify that in some way. I personally prefer this idea of appointing a manager and guardian of some form who you would expect would understand the person's wishes. But even there you have difficulty, I think, in the same way that I was talking about an advanced care plan completed by someone just sitting around the table having a chat with their loved ones - which is an appropriate and proper thing to do, by the way - but fills something out and doesn't necessarily use medical terminology and doesn't have a particular illness at the time. Just as that can be a problem I think we must wonder what kind of conversation the guardians themselves may have had with the person that might have given those indications, but of course the guardian being a person who knows them well and who is helping to interpret the directions and the information that the doctor is giving them and to accept the recommended course of action I think may well be a very good thing, but I guess that depends on the individual themselves very much.

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**CHAIR** - Paul, my question is in regard to your summary. The whole drift of your submission, which is excellent, is the need to give people a sense of wellbeing built upon a greater confidence that their wishes and needs will always be met. How do you see that being achieved? How do we do it?

**Mr RUSSELL** - I am good at raising the questions, Joan, but I am not so good at giving any concrete answers, to be honest. I think there is probably need for a public awareness campaign of some sort. To me it would be a really good idea if there was a program whereby GPs were encouraged to take an extra long consult with a person for the sake of having conversations about advanced care planning, even if it was just to make them aware of it and leave them to make the decision for themselves. As I think I have pointed out, if we adopt this idea that we have regular intervals of these chief moments in people's lives - when things are changing, when their residence is changing, or they have a diagnosis or whatever it might be - if we deliberately take those opportunities as they arrive, I think we will get better outcomes generally.

In terms of palliation, it is a difficult thing. Nobody wants to talk about death; perhaps we should. I always find myself talking a lot about it, so I am probably quite a boring person, but we do need to encourage people to talk it. There are plenty of things that palliative places do; they have their own 'death cafes' - it sounds terrible - and organisations who are dying to talk and various programs to encourage people. But even then it is a bit like the manufacturer's warranty, as I pointed out, you don't go there unless you have a need to. I would endorse any kind of public advertising campaign that the Department of Health would consider to give people the confidence that when they need something, it is going to be there.

It is a bit like an insurance policy in that sense; you have a sense of security that comes from that knowledge. It does not need to be any sort of sophisticated knowledge of the service - good advertising companies can put these things together and spin 30 seconds into a really good story. I think that, as a society, we could and perhaps should demystify in a very subtle but encouraging way what might happen at the end of life for various people.

**CHAIR** - As a supplementary question, Paul, we have received some quite confronting evidence that people are saying that their loved ones have not had their needs met or their wishes have been not considered. From the evidence we are receiving, a very significant number - a far higher frequency than I would have thought - of people are alleging that people have died earlier than they should have done. In that context, how do you we give people the confidence that their needs will be met?

**Mr RUSSELL** - I can only offer reflection on that. In my work, I get calls almost every month from a person in a panic because they think the doctor is doing something they should not be or they reckon their aunt is being euthanased or some such matter. In every case, I think I can say confidently what we have been able to uncover and discuss with these people is that it all came down to a matter of conversation - the kinds of questions not asked, conversations not had, busy doctors, people not hearing what they have been told. It really does, in most cases, I think, from those examples, come down to a matter of communication. It would be little more than that, to be honest. I can remember one instance in particular where I was at a soccer match that my son was playing in, and I spoke with a man whose father was dying. He asked me, and I said, 'Did you ask the questions you are asking me of the care team?'. He said, 'Well, no.' I said 'Why don't you?' He did and he came back to me the next week and he was very satisfied and rather warmed by the whole experience. The father died quite well in the end and he was satisfied that the care was sufficient.

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There were a lot of stories of personal grief and problems that were submitted to the recent Victorian parliamentary inquiry and they're important to read but at the end of the day - and I find no cause to question what the people are saying; you cannot say that - but there is often information that's missing. Sometimes events might, for example, have happened 15 years ago, or they decided not to take palliative care and therefore passed away in difficult circumstances. All of these unanswerable and imponderable questions unfortunately do colour a lot of these stories, so I think whilst they need to be heard, I do not think they necessarily always point to some kind of maladministration or medical practice. It may well simply be a matter of poor communication.

**CHAIR** - And the grieving process?

**Mr RUSSELL** - Indeed, yes.

**Ms OGILVIE** - Paul, as you would appreciate, there is a great diversity of opinion in relation to palliative care and how much space it fills and a question, separately, of whether some sort of euthanasia service might eventually emerge. I wanted to share with you, and get your thoughts on, the two philosophies that seems to have come through some of the conversations at this table. There is the dying-with-dignity conversation, where palliative care is seen as a continuum that leads towards a final, last resort option of euthanasia. Then there are other views - I think Margaret Otlowski was in a different camp, even though she does support some sort of euthanasia service - saying if ever it were to occur, it would be quite separate. It is not a continuum. Even around this table, we have different views on everything as well, but do you have some input on that question?

**Mr RUSSELL** - I certainly respect Margaret's opinion. I think she is a fine researcher and academic. I think we go back to this question of intention again. The intention of palliation is to make someone comfortable to help them to live until a natural death. It doesn't sit well with me to consider that those who we deliberately charge with looking after us in those circumstances could also be seen to be people who effectively end people's lives.

The confusion, I think, sometimes lies in the fact that we see the act of euthanasia as being a compassionate act. But the reality is - and I think this is a philosophical point, so I will leave it with you to mull over - the motivation is compassionate. I would accept quite easily that people who advocate euthanasia are doing so from a compassionate motivation. I certainly believe that what I do is from a compassionate motivation. But the intention, in terms of euthanasia, is to take that compassionate motivation and actually intend to kill someone - or intend to provide them with the means to kill themselves. I don't think that sits well together at all. I think it grates on people's minds. I think if we are building up a conversation that gives people confidence in palliation, I don't think it would sit well. I certainly don't want to see euthanasia laws at all, but I take Margaret's point that if you were going to have them, if you wanted to maintain public confidence, you would do it separately, somehow. As I say, I don't agree with it but I think it would have to be the case.

**Ms OGILVIE** - Yes, that is where I am at intellectually on that argument as well.

**CHAIR** - Paul, would you like to sum up before we close?

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**Mr RUSSELL** - Only to say that I am very, very grateful for the opportunity. I didn't consider that my submission would be anything other than corroborative for submissions that were probably more significant and with more particular knowledge of the Tasmanian situation. So I am grateful for the opportunity. I certainly do encourage support for palliative care. I think it is important in the work that I do that it is not only seen as trying to something but also trying to build something. I think a compassionate response to all of our needs to be developed from a whole of society perspective. Palliative care needs to be available to every citizen on an equal basis, otherwise we could easily be accused of allowing euthanasia where people didn't actually have full choices that we all expect these days from our medical services. I encourage you in your work on it, and I thank you for the opportunity.

**CHAIR** - Thank you very much, Paul.

**DISCUSSION CONCLUDED.**

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DISCUSSION WITH **Dr BRUCE RUMBOLD OAM**, LA TROBE UNIVERSITY, VIA TELEPHONE CONFERENCE.

**CHAIR** - Thank you very much for putting in your submission and speaking with us today. It is greatly appreciated. A 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 the fear of being sued or questioned in any place or court out of parliament. It applies to ensure that parliament receive the very best information when conducting its inquiry. It is important to be aware that the 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 proceeding. This is a public hearing, members or the public and journalists may be present and this means that your evidence may be reported. It is important that should you wish all or part of your evidence to be heard in private, you must make this request and give an explanation prior to giving the relevant evidence.

**Dr RUMBOLD** - I began in the very early days in the hospice movement in the UK and then at the beginning in Victoria. The calls which grew up in the 1970s about renewed care of the dying really were the basis of the hospice movement right around the world. They were grassroots community-developed programs which had their own idiosyncratic shape and constitution and methods according to the district in which they grew up. Palliative care as we know it today is a health system adaptation of those original grassroots community development programs. We are realising now that, first of all, palliative care as we have put it into the health system is unable to address a large proportion of end-of-life care in that only 30 per cent of people dying in Australia have any access to, or any contact with, palliative, nor does it seem that palliative care can readily be expanded to meet the variety of ways in which people die.

So within the health system the sorts of responses we are looking at at the present moment tend to be basically better decision-making processes and better communication of those decisions around the end of life, and the integration of services to ensure that the health systems responses are not escalated beyond the level of need of people. Both of those are obviously sensible, effective, efficient things to do but they do not actually directly address a lot of the other areas of support that are needed. It seems to me that community development approaches that established the hospice movement really need to be reactivated in new and different ways. That would include increasing death literacy, to use the jargon at the moment about people's knowledge and understanding and stories around of death and dying. People's awareness of the personal and social aspects of dying, alongside the medical and clinical dimensions, and particularly an enhanced capacity within the community for what the health service calls 'informal care' - the care of family members and neighbours and friends for each other. It seems to me that that sort of community development is consistent with addressing the concerns being put forward by the health services about better decision making and better integration, but also goes beyond them.

I speak from the public health perspective, the area I am located in now, and to me the healthy settings approach from the World Health Organisation is a useful framework for doing this. We are already through healthy cities programs and age-friendly community programs, but the version we use in the widest compassionate communities and is essentially around asking what would a community be like if they gave a continuing place to citizens who are dying, grieving, chronically ill and so forth. With that in mind that is a program or concept that Palliative Care Tasmania has begun to roll out in the Better Caring program over the last couple of years. It seems to me that they have made a really good beginning in terms of community

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engagement and they are beginning to move towards community development. I guess the nutshell of my submission is that I really would like to see that dimension of activity endorsed and supported and funded as appropriate, alongside any other development that may be there around health care planning and better clinical care and skills.

**Mr JAENSCH** - I come to politics from a background in regional and community development, so I am very grateful for your putting this lens on it. I like a community development approach. One of the communities I represent is the very small population on King Island. They often speak about it being an absolutely fantastic place to live; if only you could be born or die there, it would be perfect. You have made reference to better access to palliative care programs. We have been hearing a fair bit about that. Can you point us to other examples or places in the world where this is being done very well, that we might study?

**Dr RUMBOLD** - It is beginning to be done very well I think in several places. The United Kingdom is the most advanced in this area, which I suppose reflects in some ways the National Health Service, but also a realisation of the limits to that service, which has been growing over the last couple of years. So there is a range of programs or projects within the UK where we are beginning to see a much greater shift toward people being able to die at home supported by family and friends, with further support from health services, as needed.

We are also seeing in the extended dying process that community support can significantly decrease the number of GP callouts or emergency department hospital visits. I can certainly send you a list of publications around that sort of territory.

**Mr JAENSCH** - That would be a useful addition to our inquiry and certainly go some way to the issues which you have raised and which are different to many of the others that we have had.

**Dr RUMBOLD** - Closer to home there is some really interesting work being done in New South Wales around the social networks supporting people who are dying at home. They were networks which were attained from community contacts, not through health services. The evidence developed around that indicates the ways in which many friendship groups have been able to very successfully care for people to enable them to die at home, and the way in which they have built social capital within those friendship groups, and a range of skills which are now beginning to be used as other members of the network or family and friends begin to die, so it has got a characteristic development profile to it.

**Ms OGILVIE** - The caring communities thinking is something that I think will work beautifully in a small place like Tasmania and Hobart. Would you mind sketching what that actually looks like? What sort of processes and structures support people in their local neighbourhoods to be engaged in this kind of thing? Are there some practical examples of how it might unfold?

**Dr RUMBOLD** - Some of the practical examples that we have been involved in in Victoria are very similar to the sort of work being done with the Palliative Care Tasmania program. We have gone into communities, often at the invitation of palliative care services or other community services, and basically done some background on 'death education'. In other words, tell some of the stories around our sociocultural history of dying and how does that relate to the sort of community and our attitudes now. Obviously not everybody comes to these things but you get a mixture of people. Some of them are immediately engaged with caring for dying people - relatives - and they are looking for some answers and background. Others just have a general

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curiosity, so you have people who are interested. Out of that interest usually you find a group of people who are interested in improving skills around how to care, what to say and so on. That is a fairly basic discussion about what to say, which often boils down to what not to say. We are interested in targeting the so-called informal listeners, or unintentional listeners, like hairdressers and taxi drivers, people who perhaps hear the stories, and to give them some idea about how to respond and how to refer people on.

After that we have really gone at a community development level into project development. We have a bit of seed funding available. Are there members of the community who, as a group, have an idea they would like to try out, and is it genuinely their idea? Have they got some ideas about making it sustainable and so it goes. We might fund that with a small amount of money which is enough to do a mail-out or an afternoon tea or something like that. From that have come a number of community projects which might include linking the historical society with a local school and trying to do a history project together, building a reflective space in the local cemetery, memorial tree-planting along roadside verges, Christmas tree remembrance stuff. It sounds a little twee but it was a wonderful partnership activity in north-east Victoria because it involved recruiting all the mail van drivers, the local libraries and so forth, to be involved in it.

In that sense, that is the bottom-up material but where we are not doing as well as we would wish to is in linking those sorts of activities with the formal health services. I think we need a context within which we have more productive conversations between the interested people in the community and the service provided for that community in a way which will start to change the way we plan to deliver services. The greatest potential for that is happening is in rural towns where people are not just providing the services, they are members of the community. In that sort of role-blurring, if I could call it that, means that in actual fact they operate as citizens as well as providers. But they do not always have enough autonomy because of our tendency in Victoria to want to roll out standardised statewide services to effect some of the changes that they would ideally make in order to improve care in ways specific to their location.

I am sorry, that is a very lengthy, long-winded response, but it seems to me that is really how community development works. You find somebody who is interested and you talk to them and they talk to somebody else.

**Ms OGILVIE** - When you arrive in a community or plan to have an event or a morning tea - we use the local hall and we started putting on coffee and put a sign up. Does it look like that?

**Dr RUMBOLD** - It is normally something which is done by local residents. They would use a neighbourhood house or local hall or a church building, council offices, or whatever tends to be a standard meeting place for that community. I guess the bottom line is that the compassionate community stuff is about trying to develop capacity beyond the health services, not in any competitive way but to pick up the social dimensions of care which are needed to complement good clinical care to make the whole package effective.

**Ms OGILVIE** - Good, thank you.

**Ms DAWKINS** - I attended an exhibition at QVMAG in Launceston last year, I think, called 'Paper Garments from the Grave'. That was not something you seed funded, by any chance?

**Dr RUMBOLD** - No, I am Victorian; the government keeps a very suspicious eye on what I might -

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### *Laughter*

**Ms DAWKINS** - I am not sure but I think it might have come from Tasmanian Regional Arts perhaps, but it was a most beautiful exhibition. It was garments that had been worn by people from the families of the artists. There were baby clothes as well as older people's clothes and with stories about them. Nobody left with a dry eye, but it was in the most beautiful context for exactly what you are talking about - a chance to be able to display and to be able to talk about death in a completely different way, which is why I cannot forget it because it was beautiful.

My question for you would be, how in the UK did the medical profession relate to this kind of pillar of care coming from the community? Were they concerned about the loosening of control of health and death and dying, which is clearly the domain of doctors generally?

**Dr RUMBOLD** - Some were, that is quite true, but there are others who are very active proponents. That is actually one of the features, I think, of the UK that there have been probably more medical practitioner leaders in the field than there have been around Australia. I guess in some ways the UK system too has been more intentional in involving doctors in the end-of-life care strategy, particularly with what is called the 'gold standard of care' and what they use as the so-called surprise question which is the rule of thumb: if as a GP you are seeing somebody on a visit and you would not be surprised if they died within the next 12 months, then that is the time which you should begin to introduce some end-of-life care conversation.

**Ms DAWKINS** - That does seem to be a theme that has run through a lot of submissions and if it has not run through them, then it has been the apparent gap in the care, so yes, that is a very strong message.

**Dr RUMBOLD** - My only concern about it is I reckon it would better to have the conversation earlier than that. I think in order to even have that conversation you need a vocabulary of some sort and that vocabulary is probably best learned through the sharing of stories within the family, within the neighbourhood, within the community groups. Then you actually have a way of articulating what you might want, whereas I think that when it is landed on you the first time you step inside a clinical context, it is a very difficult question to deal with.

**Ms OGILVIE** - We have had a lot of conversations about language and terminology and the death literacy side of it. I think I might have spoken to you about the use of language before. So instead of calling a woman a widow, we now will say 'single mum' - which seems to be driven by government form - and so we are unable to recognise that being bereaved is a state of being because we don't use the 'bereaved' word anymore as well. People are now talking about 'passing' rather than 'someone has died' - which none of us here like - but the language seems to be incredibly important. We have lost some of the language of death and dying which may not necessarily be a good thing. Can you shed any light on that?

**Dr RUMBOLD** - I agree with that very much. In fact, I have just come from haranguing a third-year health science students on that subject.

**Ms OGILVIE** - Bet they enjoyed that.

**Dr RUMBOLD** - We had a look at social-historical stuff. I was looking at what happened is one of the big shifts in our society, 100 years ago, and that is the First World War, which is where

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most of our old rituals met their death, so to speak, because the bodies couldn't be brought home. You had to have new forms of memorialisation when all the sons in a district had disappeared and all you had was this statue sitting there in the main street. One hundred years later we still have this language around the 8 million men who died in a four-year period of the First World War but we have no language at all around the 50 million who died in the two-year period immediately after the First World War from the great influenza epidemic. We have language around heroes and self-sacrifice and striving, and we talk about people with illnesses who battle with cancer, and who lose the battle and fight a great fight, et cetera, but we lost the language about every day dying nearly 100 years ago and we are still struggling to recapture it.

**CHAIR** - Have you identified what languages specifically that we have lost?

**Dr RUMBOLD** - I think, among other things, the capacity to live gracefully with frailty and illness rather than having to fight it all the time, would actually be a really good start. In fact, one of the real ironies of palliative care is that quite often people who in a sense 'give up' and move into palliative care actually live longer than those who have stopped fighting their illness. There is a sense in which some form of submission or acceptance is actually a much healthier thing. We somehow are just reluctant to recognise the reality of mortality, I suppose. I struggle with the language obviously, too.

**CHAIR** - So the issue of acceptance, that is very much a live issue in all forms of mental health issues, isn't it?

**Dr RUMBOLD** - Yes.

**CHAIR** - Is that what we have a context here, that death is taboo, we aren't in a good space mentally as a community?

**Dr RUMBOLD** - I would agree with that. I am not surprised our health services after the Second World War were set up to cure because there really was a lot of success with the younger population. Our major issues now are care. In a sense there is still a disjunction it seems to me between the way our health services are set up and the needs that we have within our community. To talk about compassionate communities is really raising a critical issue because, by and large, most of our communities are structured in a way which actually works against compassion in that if compassion is the fundamental social emotion by which I recognise that you and I are connected as human beings, a lot of that is being undermined in contemporary society and so there is a sense in which to argue for good end-of-life care is to argue for a philosophical seachange in the way we view society. It's the bigger picture, isn't it?

**CHAIR** - Yes. They are very interesting things we need to dwell on in what you have just said.

**Ms OGILVIE** - Bruce, do you come to Tasmania often?

**Dr RUMBOLD** - Not all that often. The last time -

**Ms OGILVIE** - You were co-opted on your holiday last time, I think.

**Dr RUMBOLD** - That's right. I was there to attend the funeral of a very good friend of mind, Warwick Ashley, who was a liaison psychiatrist at Royal Hobart. My wife's people come

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originally from Scottsdale. They were one of the founding families there. I also have another brother-in-law living Hobart so, yes, we come down when we can.

**Ms OGILVIE** - If you are around we might have more conversations.

**Dr RUMBOLD** - I would be happy to do that.

**CHAIR** - Bruce, I think that winds our questions up at this point in time anyhow.

**Dr RUMBOLD** - It has been a very interesting inquiry.

**DISCUSSION CONCLUDED.**