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

INQUIRY INTO PALLIATIVE CARE

Professor MICHAEL ASHBY, UNIVERSITY OF TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

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

Prof. ASHBY - I made a written submission to you and I would be happy to forgo any opportunity to make a speech and instead use our time together to address specific points in what I have submitted or whatever else you need to discuss with me.

Ms OGILVIE - Thank you so much for coming in. We have had a huge morning with big discussion around palliative care. One of the issues raised has been resourcing, particularly for groups such as Palliative Care Tasmania which I believe is going to lose its funding in July. From your perspective, for the groups that sit within the community and the nursing and allied professions, is there enough funding in those resources and do you have a view as to how we could better coordinate those elements? They are dove-tailing into what the medical profession does.

Prof. ASHBY - I think Tasmania has long-established, well-resourced specialist palliative care services. There is always room for improvement in any service. With the demographics I put forward in my paper - and I am sure you have heard from others - the need in our community has risen, is rising and will continue to rise in the future, so keeping pace with that is important.

When there are difficulties in the delivery of palliative care to any citizen, wherever they live in the state - or anywhere - there are two components. One is the primary care component, which is patients at home or in hospital or other facility services, and there is then the specialist input, and that is what I am part of. That is my perspective. My career has been working in the specialist services. I have studied it very much from a hospital perspective, although at the moment I am working in the community with my team. That is my role, as well as being the director.

It would seem to me that often the lack is in primary care. I don't mean that to in any way disparage anybody who does that, but I genuinely think the coverage and availability of primary care services does differ right around the country. Access to out-of-hours support and expert nursing is quite stretched. That is certainly an area the state and indeed the federation will have to address in the future. If we're saying we want to put more and more emphasis on community care, care at home and hospital avoidance - because we have to - these are areas that will have resource implications in the future. I guess I'm saying that our specialist services will need to grow to meet existing and future demand, but also primary care services are often as much the answer. If you look at episodes where things don't go so well it is often because people live in an area where those services are stretched.

Ms OGILVIE - What I'm hearing is that the need expands going forward with the demographic imperative that we know is happening, but currently you think more could be done at the GP level? More people, more resources, or is it the distribution services?

Prof. ASHBY - It's not really my place to comment on primary care resource allocation. As you know, it's not my field and I'm not responsible for it, but I would say access to general practitioners and medical advice after hours varies depending on where you are and is variable. The same is true of community nursing. If you want to improve things, I think one of the key areas is to make sure those areas are adequately resourced and covered.

Mr JAENSCH - Following on from that, in areas where there are adequate GPs and other primary care services, are they equipped, willing and actively presenting palliative care and advance care directives to people who might be needing them or are able to produce them? Is there a culture of talking about care in dying amongst GPs that you know of, or is there still a barrier there?

Prof. ASHBY - I'm glad you put the word 'culture' in there. It is a big question and a hard one to answer because it is a very complex picture. I believe our profession, and indeed all the professions, have been on a bit of a journey with this. If you graduated when I did, which was around 1979-80 in London, all we had in palliative care was a visit to a hospice. I missed it because my Australian friends took me to the cricket that day and yet I was the only one in my year who became a palliative care physician, but that's another story. Whether you look at clergy, teachers, nurses, people in all walks of professional life, they have varying degrees of comfort in death and dying, just as they do with other sensitive aspects of human life. Some of my colleagues graduated at a time when there was not a lot of formal education in the undergraduate curriculum.

There was not a lot of role modelling around the importance of palliative care. There is almost like a lost generation there. It is not just about knowing what to do. It is about the culture, the attitude. There would be some for whom that cohort effect is operating.

I think there are some health professionals, I would not just stick to doctors, who would rather avoid dealing with death and dying. That is alive and well, although it has been changing quite fast over the past few decades. Because this is dependent on not just skills, but personal attributes and attitudes and dispositions, I think it is variable, the degree of comfort and engagement that doctors will have.

As I have said in the paper that I appended to the evidence, some of the biggest barriers we have are this idea that you cannot talk about death and dying to people because it will kill them, it will be too frightening. There is an assumption that people cannot handle it, and I think that is flawed. Certainly there are times where you have to respect where your patient is at and meet them where they are, not where you think they ought to be.

There is no doubt that the profession is based, as you might expect and hope, that medicine is constructed on the mission, if you like, to avoid death, to make people live longer, to rescue them from serious injuries and to treat chronic diseases and to try to cure them. That is still the dominant ethos.

That works really well if you have a critical accident and you get better. It works really well if you have a single-vessel heart event and you have a stent in our hospital and live for another 25 years. Those attitudes do not work so well when you are dealing with somebody who is dying of cancer, or heart failure, or respiratory failure, or any of the others. There is that construct that makes doctors struggle with opting out from an attempt to cure the patient.

Mr JAENSCH - Is this compounded when, in some areas in particular, increasingly our primary care workforce is made up of overseas trained doctors? I am not quite sure if there is a way of characterising the traditions that are embedded in their training, but I am wondering if there is another cultural barrier there to address if we are going to make palliative care more accessible and more talked about and offered in a primary care setting.

Prof. ASHBY - Your degree of training and the amount of work you might do on attitudinal issues in training around death and dying would probably vary according to which university you went to and where you trained. That would hold frankly for certain parts of Australia and New Zealand and the UK and all around the world. It is to some degree culturally determined, I would certainly agree with you.

Given that these are very subtle, nuanced conversations, I think it is generally very hard. Having worked as an English doctor in Paris in my final year of training, and having grown up in France for three years and thinking my French was very good and that I would be able to conduct clinics in French, I actually found it very difficult, surprisingly difficult. Part of it is just getting on the right wavelength with people and the nuances and subtleties of language, to say nothing of the technical language involved.

I think with our overseas-trained graduates, where there is the opportunity, we do work with them on that because different cultures obviously have different thresholds for discussing these things.

Mr JAENSCH - Do we have the opportunity to engage them? Where is the entry point for us as a state to be having that discussion with people who are in practice now, who have finished their training and they are working?

Prof. ASHBY - All of us involved in palliative care, and I have been doing it since 1989 in Australia, have been involved in education. If you look at the early setting up of the hospice movement, the golden days at St Christopher's in the 1970s, they always said the first thing is that you look after patients and they always have to come first, but they always saw themselves as being an educational, if you like, a demonstration game. A little bit like a master class - this is how we think it should be done. So that what was always in the mission.

It still is to this day. My predecessors here in Hobart have always done post-graduate education. There is something interesting about that. By and large professionals choose their own post-graduate learning programs, indeed they encouraged to do so in the life-long learning model. Perhaps if it is something you do not like you might avoid it, we all do that with study, if you can choose not to study the subjects you do not like you would do it, wouldn't you?

Mr JAENSCH - That is right, thank you.

Ms OGILVIE - This morning we have been talking about normalising the legal framework around the advance care directives. Do you think that that kind of national conversation could help bring these conversations to the fore?

Prof. ASHBY - A national conversation?

Ms OGILVIE - Yes. If somebody was to move state, for ease of access of records to have the same advance care directives all around Australia as the one you had in place here in Tasmania, if your end of life care was in Queensland, how would that relate?

Prof. ASHBY - As a preamble to that, I have discovered I am an English common law kind of person rather than a continental statutory nail-it-down-with-code-and-statue, the sort of Napoleonic approach. The reason I say that is that I don't think a national consistent law would be that useful. I can give you an example. In Tasmania you have quite a lot of people who have spent half their lives in warmer places up north. I have seen a couple of people come down with the Queensland thing, which is the size of this.

Do I look at that and say, 'I can see here you want this that and the other thing during your entire time, and by the way I think it is game on, it is happening now, which you are not going to get back'? Do I say, 'Sorry, we are in Tasmania, so too bad'? As a doctor my ethical duty there is to extract from that guidance as to how to relate to that patient and how to respect their wishes. I take the Queensland document and I eventually find out what it actually says and I implement it. My sense is that one is better to appeal to the ethical duty to implement - assuming capacity is lost - to implement what you know of the patient's wishes, if that is expressed in other jurisdiction's document.

Having sat on a national technical subcommittee of AHMAC, the Australian Health Ministers Advisory Council, we talked about advance care directives. I think a lot of people in the room did think that national standardisation is a good thing. I suppose I don't really think standardisation is an inherent problem. I think it would be very difficult to get uniform law in Australia or any federal countries. It would be a huge undertaking. The important thing here is because it has to line up with all the other states' guardianship laws and other laws. It is not impossible, but it is a very big project and I am just wondering whether it would really change anything. There are other reasons for that, but we might come back to those, about the effect of the advance care directives.

CHAIR - Michael, is the national database of advance care directives more relevant?

Mr JAENSCH - The registration.

CHAIR - Yes, the registration of them so that they can be identified?

Prof. ASHBY - Well, as you know, in a sense, Tasmania is the social laboratory for that. We are one of the very few places on the planet that requires registration of enduring guardianship forms. It is a significant administrative and financial cost on a jurisdiction. I am not sure what it adds. I can safely say that I have been practising in the state since we moved here in 2007 and I can't remember a time when going to the Guardianship Board and getting a copy of the enduring guardianship document has been a game changer. Our social workers in our hospital - in the more acute end - may have a different experience, but it's not what I'm seeing and hearing.

CHAIR - In a more contemporary sense, with it being on a secure database, can treating persons can go online and find that care directive if their person doesn't have it with them? Importantly, when they are perhaps in the acute stages of dying and people wanting to get verification of what their actions should be?

Prof. ASHBY - I used to think it was a good idea, but I'm not persuaded now. In order for that to be really useful I think you would have to have a proper integrated national electronic record and we don't. Funnily enough, I think we are further away from it than we were a few years ago. As far as I can see it has been the most extraordinary white elephant, by far. Years and years, millions of dollars, demonstration projects and heaven knows what. I registered for my own - I was approached at an Australian Medical Association meeting and asked, had I registered and do I have my own record? It is the last I have ever heard of it. It is a massive undertaking and I shouldn't jest, but I think until you have that kind of electronic record up I am not sure how that system would work.

Even here we have a digital medical record at the Royal, as you know, and you see amalgamating with our service into the Tasmanian Health Service. Having the recent goals of care form up there on the alerts, I think is valuable. Having the advanced care directive there I think is valuable, so it is visible when you come in. It removes the onus of the people bringing it themselves. I would say informed and armed citizenry who informed their relatives, their person responsible or their enduring guardian, 'Here is my advanced directive, here is my guardianship form, here is where you find them when I am sick', lodging them with your GP and making sure any of your health attendants - when they are taking a history from you - know that you have these things makes a huge difference.

I know what you are driving at and it sounds sensible. If you go to any emergency department and somebody comes in - we have heard that people's wishes are not always respected - wouldn't it be wonderful if we could immediately locate the forms and there it is in black and white. When our medical record system is up to that then maybe it would be.

Ms OGILVIE - We have heard a lot about this this morning, about the opaqueness of some information and how access to that information for some is easier than others in the system. Have you experienced a time, or do you think there could be an issue with the advance care directives that are prepared at one stage of life? Then, say, a 50-year old produces it later on when circumstances have changed so fully that a different set of circumstances are in place. The updating issue would seem to be part of the problem - you would not want the information effectively set in stone, and then you would need to reflect what was currently going on.

Prof. ASHBY - That has been one of the big objections in the medical world. A lot of my colleagues have said that is exactly the problem. You make the directive when a certain set of circumstances applies and when it is needed, those things have changed.

I guess this is where my common law mentality comes in again. You cannot legislate for every situation. You cannot foresee every contingency. So what I would say is this. When you are making an advance directive - I vividly remember a young patient. I made a film about her in Melbourne years ago, Amber Turk. Amber said I never want to have that masked bit, like that machine. I never want to have that again. She was very specific. We put that in an advanced directive because it was likely to happen. She was very clear she did not want it. She knew the implications of not having it and it was really important for her to know that was recorded in her advance directive.

For most of us, we can have some idea of what might be around the next corner but actually we do not know. I would say if you are making an advance directive, make it more principles, values, beliefs and, perhaps, outcomes I think are the most important. I think William Molloy, from Canada, his book *Let Me Decide* in the early 1990s, I think from memory. He was very keen to say don't say you never want another operation because the one thing that might happen to you is you might break your hip when you are 89. You lack capacity, and the only way to make you comfortable would to pin it. So don't say you never want any operations because there might be an operation available to make you comfortable, rather than make you live longer. That is one example of how flawed that can be. Obviously if you say I do not want another surgery operation full stop, yours sincerely, the principal, signed, sealed and delivered - fine, absolutely.

Another big milestone is obviously when you are diagnosed with serious disease. Most of us are cruising along in life. That is one type of directive. Then, you get cancer or heart disease. Then there are certain things likely to happen. Kidneys are a very good one. If you are diagnosed with kidney failure there is a chance you are going to come to the point where kidney dialysis will be a real decision.

Ms OGILVIE - I have a constituent with this issue, a 92-year-old with this issue.

Prof. ASHBY - Yes. The thresholds for dialysing people have changed and not always for the better. That is another matter. There you could say you never want to have dialysis. That decision is most likely to occur at a time when you do have capacity, you are likely to have a person responsible and contacts arranged to help you make that decision.

Are you going to be relying on a bit of paper? I suspect not. It is the most powerful position to be in - and I have to say Tasmania has very enduring guardianship legislation - the only problem is that it is a bit of a procedure to get the thing done. Most people don't bother. We know that.

Ms OGILVIE - Or don't even know that is an option.

CHAIR - Forget to sign the last.

Prof. ASHBY - Even if they did, they don't get around to it. They miss the last bit. It is there behind the mantelpiece clock. Damn, I did not get my enduring guardian to sign it. Bad luck. Is it valid, is it not?

CHAIR - Or send it up to the board to register it.

Prof. ASHBY - Exactly right. It is a very well constructed thing. I think the sensible thing is it has the fallback position of the person responsible and it defines that. It gives a hierarchy of persons. I think that is very good.

The best position to be in is to appoint an enduring guardian, clearly. Then in the space on the form where it says are there any specific conditions you put your advance directive in there. When the time comes you have belt and braces, if you like. You have a person who is there to speak for you in law as a person responsible and you have backing documentation if there are any particular directions. I would have thought that is the best position to be in but realistically, that is a minority position. At a practical level, at least we have this framework where you have the hierarchy and that person is responsible. It is very good to see that not lost in any way.

If you are talking about an advance directive, those are the things that are my guiding principles. State what outcomes you wouldn't want to see. I think William Molloy's words were, 'If I can no longer recognise my family and friends, if can no longer eat myself, if I can no toilet myself.' Those were some of the key headings, thinking particularly of dementia, which is the huge new happening thing.

Ms OGILVIE - I would love to hear a bit more about that in your practice.

Prof. ASHBY - I preface it by saying we are fortunate in Tasmania to have the Wicking Institute, of which you would be aware. I would not steal their thunder because they have world-class expertise in that field. I was talking to a senior academic in this state recently about her experience with her mother and dementia and reflecting on the fact that how it has come really from nowhere to be the number three cause of death in Australia. There has been a 140 per cent increase, I think it is, over the last six or seven years with the ABS either as the single reason or part of multiple death causation.

If you are working in palliative care as I am you can see this change. We started off focusing predominantly on cancer symptoms and while that story remains very important and a core part of what I do as a specialist because it is challenging, we are seeing this large number of people where the key ingredient is the remorseless, global decline of dementia and the decision-making that is then required in that. Bear in mind, I only see people at a very late stage. I do not see anybody at the earlier stages because it is more aged care and general practice that deal with that. I have done some work with the Wickham Institute where what we have been trying to do is help carers, families and health professionals to understand that dementia is a fatal process and unless one of the other comorbidities results in your death beforehand you would die as a result of the process of dementia.

CHAIR - My understanding of dementia is that it is a mental decline. What is it about that which causes you to die?

Prof. ASHBY - In pure forensic, empirical terms, there is a bit of mystery in that question. There are different types of dementia, so different parts of the brain can be affected, but what seems to happen is that when you progressively lose that high level executive function; gradually all your life processes start to be affected. At the end, whatever the pathology and process, it becomes a process of not being able to engage in life, not being able to eat, not being able to drink and not really wanting to get up and do anything. I say it is a mystery because there is a part of the dying process I think doctors and scientists do not quite grasp, and it is to do with what you might call, in an unscientific way, the life force which you can see in people who are dying.

I have these conversations with people now and it is funny how it has opened up a whole new conversation with people about the dying process, whether it is cancer or airways disease or whatever, it is a gradual distancing from the world. We talk about petrol in a tank. I have asked people, 'Do you feel like you have a ration of petrol every day?', and they say, 'Yes, it's a bit like that'. Do you feel like it gets a big less every day? Yes. When it's spent it has gone and you can't get it back. When you are young and tired, if you had run a race or something, you can go around again, but the sick, elderly, frail, aged person can't. Those things become more and more progressive. With dementia you see them sitting there, not wanting to engage. That neurological cognitive impairment seems to affect the whole body. On top of that you have the fact it doesn't usually happen alone; it is usually part of, say, heart disease, lung disease, kidney disease, diabetes or cancer that comes into the mix. It is a complex, whole-of-person process. The questioning of the precise mechanism is quite understandable because there are some things we just don't get about the process.

CHAIR - What is the best care for those people so that they die well?

Prof. ASHBY - First of all, like all of this, it is a recognition by all the people in the equation - those close to you, family and friends, community, your general practitioner, nursing. If you work in a facility, it is understanding that it is a slow dying process so the aims of care need to be proportionate to that and that comfort end points are put first. For instance, pain assessment in the elderly can be quite difficult if they have cognitive impairment. We rely on a verbal history. There is a scale from one of my former colleagues in Adelaide called the Abbey scale which uses smiley faces and symbols rather than words to try to evaluate pain. Good nurses and carers who are experienced in aged care will tell you that when they move the person they grimace; they can sense it. They can see their face and the body moving and that's how you work it out. We need to be addressing that. To be fair, there is a growing awareness now.

Ms OGILVIE - On the pain issue, we have had a lot of input already and there is a discussion happening around whether the community understands the range of pain options. From your perspective, do you think all pain is able to be managed at the end of life or do we still have circumstances in which somebody is under the care of palliative specialists but their pain isn't able to be managed? What has been your experience?

Prof. ASHBY - We have gone from pain in the elderly to the bigger question of whether all pain can be managed.

Ms OGILVIE - It seems to be a big part of the conversation.

Prof. ASHBY - There isn't a single area of medicine that has a 100 per cent score, so why would palliative care be any different? Any claims by us that we can relieve all pain are patently nonsense. I think it is very foolish of certain people in our specialty around the world to convey the impression that they can. I don't think anybody these days would make that claim. What I can say is that we can nearly always make a difference for the better. There would be very few situations in which I would say there is nothing I can do for pain relief. All good drugs act on the brain and there will be side-effects and sometimes doctors are very good at minimising side-effects. The problem is that in our residential facilities, because there have been some very unfortunate incidents with over-sedation and falls. You would be well aware that this Parliament and this Government is responsible for one of the most regulated industries. You go into an aged care facility and there are shelves groaning with large tomes of rules and regulations and reporting mechanisms. It is quite overwhelming. Within that there has been, rightly at one level, a very big push to prevent the over-sedation and inappropriate sedation of the elderly, but it has made practitioners very wary of giving drugs for pain relief and drugs in the dying process when sedation is often needed.

Ms OGILVIE - When perhaps they ought to. Has it had sort of a reverse effect?

Prof. ASHBY - I think it might have done. I think it has.

Ms OGILVIE - It can scare people.

Prof. ASHBY - Yes. I think what you have to do is warn people. All medicine is risk. One of the prime duties we have is to make sure that people know the risks and the benefits and that we give good advice to people based on that ratio, if you like. With pain relief in an elderly person, say, a trial of opioid analgesics - if that is appropriate to the situation - you do have to advise that you'll start very low doses, but even those can upset people. You work from there.

If you are going to address the issue, all of the drugs have side effects. The anti-inflammatories - which can be very useful for an ageing skeleton - can have potentially lethal effects. I would say if you are in an aged-care facility and if you are in pain, there comes a point where comfort needs to be put first, just as we do in palliative care.

We are not going to be reckless but we need to focus our care on the comfort, not on longevity. That is the key to all of this. There was a wonderful article in the *Atlantic* about two years ago, the *Atlantic Monthly*, I think it used to be called, by a public health academic called Ezekiel Emmanuel, the brother of the mayor of Chicago, a prominent figure in bioethics in the US. He said that he thought given that the prime dying time for people in the US is 75 to 85, which it is here as well. When you got to that age bracket, it was not that you gave up on life and never had any more treatments, but your priorities for healthcare should be beginning to change. Rather he said, 'Mine would,' and he was obviously encouraging others to do so. That had a very big impact over there - as you can imagine - politically, because he was quite close to the White House.

It was seen to be that you are telling people to check out of healthcare for economic reasons. It was a big storm. The article is really worth reading because what he suggests is rather than it being a politically initiated reflection and policy drive, the really important thing is to make sure that people in the community understand that it really starts with them, what their expectations are, and what can reasonably be delivered and what cannot.

If you are in that age bracket and for instance, you take the Reem example and say, prior to 75 I might say, well, I will have dialysis. The age cut-off is a problem because you cannot be agist and we should not be, but somehow we have got to put some parameters around the argument. Once you get into, say, the prime dying time of Australians, would you then want to go onto three days a week dialysis, for instance? To address it from that point of view, people say, 'I think now at this stage I would not want to. I will have palliative care so I can get comfortable through the process, but I do not go onto dialysis'. It is about changing people's expectations and showing them that the outcomes aren't always that good.

There was a study in Ontario in Canada last year suggesting that a big slice of the health dollar is spent in the last year of life. We have always known that. If my extrapolations are right, and it might need a big of adjustment, we could be spending anywhere between $20 million and $40 million even in a small state like Tasmania with 4000 deaths a year on the last year of life. If that is buying people good care - and in particular good palliative care - that is great. If that is what it costs, then that is what it takes. I suspect that in that there would be a lot of attempts to prolong life that buy people an expensive dying process that they really do not want, but they get into.

Mr JAENSCH - That brings us back to knowing what people want story and the barriers to that. When I consider the demographic that I represent, in the breakdown of people in my electorate where there are very relatively low levels of literacy. These people do not know how to ask, what to ask for or how to make inquiry. A lot of people die without ever knowing that they could have these other levels of care. When we are providing that, if all of our information and advice through processes like this says it is desirable and possible to offer - a bit like education - how do we make it available to people as a right? If quality of death is a right, but we can't tell doctors that they have to provide it, because you can't tell doctors they have to do anything.

Prof. ASHBY - That's about right.

Ms OGILVIE - Men, generally.

Mr JAENSCH - There are women doctors also.

Ms OGILVIE - Yes, I am teasing.

Mr JAENSCH - How do we do that? I am picturing people who I know in my electorate who don't get out of their houses. They receive their care in response to emergency circumstances each time and might not have other people, or persons responsible, to nominate. They might not know how to go because they don't have to do that either. There is no one who goes around and checks at census time if you have a person responsible.

Ms OGILVIE - Or if your person responsible has actually deteriorated themselves.

Mr JAENSCH - But you need to have a dog licence.

Prof. ASHBY - My experience of working in Australia with the Anglo Australian accent with the slight English ring to it, I have not found really anywhere in the Australian working class where if you hit the right note with people they don't get this. In fact, sometimes I find wisdom there that I don't find in the more affluent parts of the community. It is trying to connect with people and use language that they can relate to.

I remember one man in South Australia. I was trying to beat around the bush a little bit about what he knew about his condition and I said, 'How do you see the future?' and he said, 'I haven't got one'. Another one said to me, 'I'm cactus'. People who have worked on the land, I know it is a laboured idiom, but there is a sense of life and death, being close to nature. I think those are the sorts of things we need to appeal to in personal relationships as health workers. When you address it like that with people in simple, everyday, vernacular language I have not really found any great difficulty.

Mr JAENSCH - If you do, though. If their doctor doesn't, it never happens.

Prof. ASHBY - I might make one concluding remark that I think draws together the threads of the conversation we have had this afternoon, and thank you for listening and taking such a keen interest in this area on behalf of the electorate, it is important. I was involved with an initiative called Healthy Dying, which is referred to there in the material. It was actually endorsed by the Department of Health and Human Services. That was really important because I don't think euphemisms help. I don't think the public need us to hide from them the fundamentals of human existence by wrapping them up in euphemisms. If you look at Australia's public health campaign record, we didn't reduce the road toll by beating around the bush, we showed the most out-there TV commercials in the world, which then became the gold standard everywhere. We also didn't work with the AIDS epidemic by avoiding the hard issues, even though it was socially very controversial. I would strongly urge us to try to get away from the 'passed away' kind of euphemism that is quite interesting.

CHAIR - We are in agreement on that.

Prof. ASHBY - It is almost as if everyone is trying to protect everybody else. I think it is important to have an initiative hopefully within the whole of government that names up dying for what it is. The public can take it because they know it happens, they know it is the fundamental reality of human existence. I think it is very important to work, as I have detailed there, with the sort of concepts that Allan Kellehear brought to us a decade or two ago in his books, and have a true health promotion model where we name it up.

CHAIR - Thank you.

THE WITNESS WITHDREW.

Ms MARGARET SING, **Mr BILL GODFREY** AND **Ms HILDE NILSSON**, DYING WITH DIGNITY TASMANIA, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

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

Ms SING - I am the President of Dying with Dignity Tasmania. Hilde is a committee member, a long-term committee member, and also a retired nurse with quite a lot of experience in the advance care directives area, having done some work through the Hospice and Palliative Care Association as well as Dying with Dignity Tasmania. Bill is vice-president of Dying with Dignity Tasmania and also the person who has driven the whole advance care directive end-of-life planning agenda and action for several years. He has also developed the practical guide as part of that process.

Mr GODFREY - I have two other reasons or elements that may be helpful to the committee not related particularly to Dying with Dignity. The first is that you may remember the assisted suicide of Elizabeth Godfrey in 2002 which led to the trial and conviction of my brother for assisting in suicide. I have brought along, in case you happen to be interested, a detailed statement of the situation leading up to and the consequences of that, because I believe it is a very powerful illustration of what can happen when things go badly wrong.

The third thing that may be useful is that I was a management consultant for 40 years, the last 10 of them very largely working in the health industry. If I may, Mr Jaensch, refer to one of your last questions. I am currently doing a little bit of return work with a Victorian-based community health care organisation which has done enormously good work in a country area to deal with the problem of isolation essentially through running a whole series of very clever training programs within the community, so that they know how to contact the person and how then to feed back what needs to be done. It is a very good example of what I believe could be done very widely in Tasmania.

Ms SING - You have received our written submission and I will refer to it but not go over it in great detail. We are pleased to be following Professor Ashby because I think we are extremely lucky to have somebody of his talent and experience in this state. The standard of palliative care we have is in no small way due to a lot of his work and initiatives like Healthy Dying and so on. I also want to pick up on that last point he was making that we do not get significant progress by avoiding the hard issues. I guess that is our major aim today.

We can see from your schedule that you are going to be receiving a lot of good information from people like Professor Ashby on what is happening. We want to make sure the people who may not be benefiting from that, not because of the lack of good intentions or really good services, but there are people whose end of life is not anywhere near as good as it could be. We see no conflict between a voluntary assisted dying legal option and palliative care. In fact we support a last-resort option of voluntary assisted dying. I pushed very hard in the preparation of that 2013 bill and continuing with the 2016 bill to have a last-resort provision in there.

Ms OGILVIE - What does that mean?

Ms SING - If you look at the 2013 bill and when the 2016 one comes out, in section 22(2) and (3), at the last part of the process, the doctor and the patient have to together agree that there is absolutely nothing else they have been able to find to improve the person's condition or relieve their suffering adequately. The whole thing we have pushed, as a committee and organisation, is about the people who have run out of options.

CHAIR - Can you identify that bill for Hansard?

Ms SING - It is the Voluntary Assisted Dying Bill 2013. It was a private members' bill, moved by Lara Giddings and Nick McKim.

We have no sense that there is an either/or here. Voluntary assisted dying exists on a continuum with everybody doing the best they can to find the best way to assist that person to have their wishes met and to live as long and as well as possible and then to have the best death possible under the circumstances confronting them.

Professor Ashby may or may not have referred in his submission to an article of his that has only been published very recently in the Queensland University of Technology *Law Review*, volume 16, issue 1. I can provide a link to it, if you want it. It is called How We Die: a View from Palliative Care. It is an excellent article, as you would expect. In it he refers to the issue of a 'good enough death', and for some people that is all that can be achieved. One of the other professors working in this field, Professor Battin, talks about the 'least worst' death, given there is no conflict between assisted dying and palliative care or other medical treatment, but it's at the end of the process. The other important fact is that wherever assisted dying is a legal option it is very rare. It is important to look after the 97-99 per cent of the population. The benefits of palliative care and the continuous improvement of palliative care and the broadening of services, and the continuous improvement in advance care directives and so on is going to be a long process that needs to continue, but we believe that additional option needs to be there.

One of the things I have done recently is follow through the Victorian inquiry into end-of-life choices. It is an excellent resource. One of the things in the submissions of those people who are opposed to assisted dying, which I find almost incomprehensible, given the major opponents are religious and/or medical, is that I cannot find a single mention - and I did a very detailed exploration of more than 20 submissions - of the people whose suffering continues because palliative care cannot meet it. They talk about pain and say, 'Oh, pain can be relieved'.

Ms OGILVIE - So that you're aware, we have had some conflicting evidence on that.

Ms SING - There is a focus on pain rather than the broader notion of suffering, that it is either pain or existential suffering with none of the physical suffering in between, that it is a choice between offering the relief of palliative care, or all of those things. I find it extremely disturbing because, quite frankly, if I was going into palliative care I would not want to be treated by somebody who didn't believe, or was not being open and honest about the fact that they could not relieve all suffering. There are a lot of descriptions of the aims and purposes of palliative care, the methods and improvements, but I don't believe any system can really improve as well as it should be able to without admitting that there are people for whom whatever we do is not going to be good enough.

Ms OGILVIE - If you're expanding the definition of pain to broader suffering, what do you include in that?

Ms SING - We referred in our submission to the Palliative Care Outcomes Collaboration and there is some excellent data on that website operating out of the University of Wollongong. I don't know whether you have had a chance to look at any of the reports but this is Trends in Patient Outcomes: Palliative Care in Australia 2011-15. The sort of symptoms they report on are these: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. There is a whole range of physical suffering. Having had the experience of my mother dying over an extended period,that is only the tip of the iceberg because it is the whole combination of things. Everything from mouth ulcers so your teeth cannot fit and so you can't eat properly. There are so many things that happen to people at that time of their life.

The important section, I was gob-smacked by when I came across it, was as part of this process they are looking at patients with moderate or severe distress from pain. This is just pain at phase start who have moved from that moderate or severe situation to either absent or mild pain. Only 50 per cent, their benchmark is 60 per cent across thousands of palliative care episodes, only 50 per cent of people are getting that relief. Being able to move from moderate or severe to mild or absent. There is no mention of that in a lot of material that is coming through from palliative care.

These are not our figures. These are national figures collected across a large number of services - inpatient, community and so on. The point is it is very important that recognition is there. That although palliative care is improving, has improved a lot, and the graphs show that very clearly here too, there is a process for continuing that improvement. Despite their best efforts there are still people - even though there are only a few in percentage terms, it only takes one per cent of deaths in Tasmania to be forty people - in a really bad situation. That is a basis for the kind of concerns we have. That circumstance is really critical to be recognised.

CHAIR - Margaret, are those documents publicly available?

Ms SING - Yes, they are.

The other really important point to make, and I am sure both Mr Godfrey and Ms NILSSON would like to comment about that in a moment, is we see a lot of support for people to express their wishes but meeting people's wishes is a very complex thing, as Professor Ashby has indicated. The whole issue of over-servicing of -

Ms OGILVIE - Doing too much.

Ms SING - It is how you define 'too much'. Once again, there are so many articles around but this one, published on 27 June, I found particularly interesting because one of the authors is Professor Hillman who is head of one of the emergency -

Ms NILSSON - Intensive care specialists.

Ms SING - Intensive care specialists in New South Wales. I can give you the references here. It came out after we put in our submission. They are referring to non-beneficial treatments. We have the notion of futility. They have tried to talk about non-beneficial treatments. To start to define what it is that are the criteria and also to move on from what is a non-beneficial treatment to look at the kinds of things that should be done in terms of clinical indicators.

Wherever you look in the health system, among academics and so on, there is so much going on to continue the improvement that we have. We are extremely lucky. We want to make sure that people don't miss out. The needs of people who through no lack of effort and skill are left in the situation where without a legal assisted dying option their deaths are very much worse than they might otherwise be. I will not go any further into the arguments around that.

CHAIR - I might open it up.

Ms SING - Perhaps Hilde could say briefly, I know they both have a point to make.

Ms NILSSON - I retired from the acute care sector five years ago and for the last three years during my work in the acute care sector I had a clinical role in end-of-life management with also a focus on advance care planning. Subsequent to that I had a position in a residential aged care facility doing just advance care directives for the families and the residents. Palliative care is generally good as long as you get access to it. Getting access is a huge problem. I had difficulty hearing what Michael Ashby was saying.

Ms OGILVIE - There is a spectrum of views.

Ms NILSSON - Palliative care is still to a large extent cancer-centric, although that is changing. I did hear Michael Ashby mention dementia. Palliative care is grossly lacking in the field of dementia. I am sure Michael Ashby, in fact I did hear that snippet when he said that the medical profession at large was often very reluctant to talk about death and dying. That is the problem. In my experience my whole working life, some 40-odd years in the nursing profession, so often the medical practitioners treat the diagnosis rather than the person. That hasn't changed over the years. I have been retired now as I have said for five years from the acute care sector, but I still have friends who are working and it is still much the same.

There is a lack amongst the medical profession of recognising the point of where what we call active treatment becomes futile and the treatment focus needs to be changed to comfort care and quality of life that is palliative care. There is some recent research led by the University of New South Wales, published in the *International Journal for Quality in Health Care*, which found that hospital doctors frequently initiate excessive medical or surgical treatment on patients over 75 with advanced, irreversible conditions. It also found that over 90 per cent of elderly patients with cancer who died in hospital were given CPR and then died. That is just gross. I just cannot find words to describe that.

In my clinical role with end-of-life management I did massive education programs about not resuscitating everybody, but there is such a mindset against that. It needs a whole culture change.

CHAIR - Could we have the name of that document?

Ms SING - It is that paper that I referred to.

Ms NILSSON - Margaret mentioned Professor Ken Hillman and a quote of his that I often refer to is:

> The suspension of death is now routine, as we demand that sick and elderly people trudge on indefinitely.

That is not good. I have done some education sessions as part of the federally funded Better Access to Palliative Care program, that I am sure you are familiar with.

One of the numerous recommendations of that is that anyone who gets a diagnosis of a life-limiting illness should get palliative care involved at the point of diagnosis. That is not happening. BAPC have done wonderful work, but I don't see much evidence that it has changed clinical practice, unfortunately. There again, it is that culture change. I firmly believe that voluntary, assisted dying should be part of the palliative care toolkit for reasons that Margaret has outlined.

You refer to, apart from pain, breathing difficulties. Unless you have actually seen that, it is hard to appreciate people gasping for breath, feeling like they are drowning every second of every day. That is one of the hardest things to relieve. It is torture. To get to advance care directives, most GPs - if not all - do comprehensive health assessments for people over 75. It is my belief that doing an advanced care directive should be part of that comprehensive health assessment.

Mr GODFREY - Too late.

Ms NILSSON - If it has not been done before -

Mr GODFREY - It should be done when you first make a will.

Ms OGILVIE - It might need to be updated depending on -

Mr GODFREY - Indeed.

CHAIR - When you first make a will? You are supposed to do that when you get married or go into a serious relationship. An advanced care directive is probably a bit early then.

Ms NILSSON - For people who have not already done it.

Mr GODFREY - The sad fact is accidents happen.

Ms NILSSON - Talking about updating advance care directives, I do not actually think that a well done advanced care directive should need much in the way of updating. The reason for that is, and I think I caught Michael Ashby saying that advance care directives should be outcome focussed. People's values tend not to change that much. It is all about what the person perceives as quality of life.

One old man said to me, 'When I cannot wipe my own backside, I do not want to be here'. The next person might be quite accepting of being bedridden and having to be fed and all the rest of it as long as they can talk to their grandchildren, for example. Another point that is often not talked about, in fact, I have seen it in print a few months ago in a copy of the *Senior's News*, where a geriatrician was saying that once you have done an advanced care directive, you are locked into that. As long as you have capacity to speak for yourself, the advanced care directive is completely immaterial.

That is an important point to remember. An advanced care directive that is done properly will say something like, 'If my condition deteriorates to a level where it is unlikely that I will recover', to whatever extent is reasonable to the individual, 'Then I do not want any treatment to prolong my life, but I want maximum effort concentrated on comfort care or whatever you want to say. It is the outcome that should be focused on with an advance care directive. People's values tend to not change that much, as long as they have capacity or are likely to get capacity again, what is written in their advance care directive isn't relevant anyway.

Mr GODFREY - On the matter of palliative care, rather than speak about that, I have brought in copies of a statement I prepared for the trial of my brother setting out in great detail the circumstances leading up to my mother's death, to which I have added two or three paragraphs about the after effects. I would prefer it not be published, but I have five copies if members would care to read them. It is rare to have a case study that covers two years in considerable detail.

CHAIR - We will take that in camera.

Mr GODFREY - I won't say anything more on palliative care. I would also like to produce single sheets of paper, which are very much a summary of the aims of end-of-life planning activities, which includes advance care and for which I will add a few points. I find the situation, which is based on Australian data, really concerning. 75 per cent of us who have not had end-of-life discussions, and less than 10 per cent of us die with an advance care directive in place. If you do have a good advance care plan it gives important guidance to medical professionals in dealing with irrecoverable health situations. Accidents happen, as soon as it's time to make a will it is time to think about an advance care directive. There are 60 per cent of us who think we don't talk enough about death. As an aside, I quite often watch that *Antiques Roadshow* and nobody on it has ever died, to the best of my knowledge. They all 'pass away'.

Mr JAENSCH - Thank goodness they did, otherwise they wouldn't have inherited those nice vases.

Mr GODFREY - More than 70 per cent of us die in hospital, although most of us would prefer to die at home. With some of us, as with my mother, it was something on which she absolutely insisted. With ageing it is all the more important to discuss these things. What we have been trying to do through this document - a copy was given, I think, to all members - it seeks to set out all the things one might need to think about in order that, if I suddenly die, my family isn't left with an appalling mess and if I suddenly can't speak for myself, they know exactly what I want said.

Some of the things in it are designed to develop their death literacy, for want of a better term. That is, think about and discuss with the family what they would want or not want if the worst happens. Secondly, make their end-of-life plan, such as a will and advance care directive, early; share these wishes with their family; get informed about life and death care options, such as dying at home, home and community-led funerals and natural burials. People have views on this but they are often not recorded. The family is then better equipped.

Briefly on advance care directives as against enduring guardian, because I know you were having some discussion about that, one of the advantages of enduring guardianship is they issue a little card which you can put in your wallet and because most of us have car keys, we mostly carry a wallet and there it is, there is the number. All anybody in a hospital needs to do is ring. Advance care directive does not do that. But in talking about it, I encourage people to make a card and put it in their wallet with the number of their GP and to make sure their GP gets a copy.

Ms NILSSON - With the Health department advance care directive form, there is a little wallet card that lists the person responsible.

Mr JAENSCH - I am sure there are now also options, in case of emergency, for a retrievable entry in your phone that is able to be accessed without using your pass key.

Mr GODFREY - As one of the side issues in talking about this, I encourage people to keep in a safe place a record of their pin number and all those things. More and more, people have vast sums of money sitting on a computer which you cannot get at. That is by the way.

Ms OGILVIE - Bill, I am very familiar with your brother's case and I have read the judgment. I have also had conversations with professors of criminal law at the university in relation to amendments to the Tasmanian Criminal Code, which I think needs addressing. Hopefully, it is a leading question, we might be in agreement on that. The circumstances were dreadful and sane and good people identified that.

Margaret, you know my perspective comes from having had the experience of a baby who died. I am very much in the neonatal and early stages of life, looking at palliative care. There is a substantial and substantive gap there, but I am not sure that is part of your remit. It seems to be the older age cohort.

Ms SING - It is people who are competent to make decisions because it is a suggestion on our part at this stage that any assisted dying or requests and directives would be made by people who are capable of making their wishes known. We do not have the experience in that area.

Ms OGILVIE - Does your group represent parents who are having to make decisions? Do you have an aggrieved parents sub-group?

Ms SING - No. We have no experience in that area that I am aware of. We were very interested and discussed as a committee, that recent case in Western Australia where the parents wishes were overridden by the court and expressed our concern about that. We were outside talking with Michael Ashby about philosophy and ethics. There was an interesting article by The Ethics Centre that related to that and the questions and so on. I am aware of it but we have not got into it.

Ms OGILVIE - It strikes me we are in agreement with the majority of things. Hilde, your experience with the gap in availability of palliative care. We have heard divergent views today on that. Is that something you think could be filled with better resourcing? Do we need more people helping or is it better communication of what people are entitled to?

Ms NILSSON - The problem is education of the medical profession. Palliative care is a referral based specialty. The reluctance of doctors to refer to palliative care is the main problem.

You can run education sessions for doctors but, like anyone who does that will tell you, the ones that need to come are not necessarily to the ones that do come.

Mr JAENSCH - Same with everything.

CHAIR - I was going to say parliamentary inquiries.

Ms DAWKINS - Hilde, you were talking about the advance care directives in the aged care facility, did every resident have one? Did most of them have one? Were they all encouraged to and some chose not to? How did that work out?

Ms NILSSON - In the four years that I worked at the residential aged care facility there were two residents who did not want to have anything to do with it and that was their choice. Everyone else in that four-year period had an advance care directive.

Ms DAWKINS - Was it a part of when they first came to the facility or was it a conversation you had once they settled in? How did that go?

Ms NILSSON - When they first came in I introduced myself, gave them a little pamphlet about it, had a chat about this, that and the other and then came back a couple of days later and just gently started the conversation, finding out where they were at. There is no algorithm for doing advance care planning, it is a very individual thing and you sort of have to feel your way. I then took it from there, but what I always did was involve the families. That, I think, is of vital importance. Where they did not have family, close friends or whoever was important to them.

Ms DAWKINS - If they were alone? Somebody who didn't have that sort of support network, is that something that you still believe can happen and be right?

Ms NILSSON - One resident was English, came as an immigrant, her husband had died and they never had children, her friends had all died and she was in her nineties. What I did with this lady, and she still had capacity, just did a detailed sort of advance care directive about what outcomes she absolutely did not want and all the staff were in on it and they all saw to it that she got what she wanted and they kept the GPs in line. That worked well. You can actually do advance care directives for someone who has already lost capacity. You obviously can't do an enduring guardianship because people must have capacity, but I have done many, many advance care directives for people with dementia or some other cognitive decline with the families on the basis of how they knew that person before they got the dementia.

CHAIR - You can do it as the third person or a specialist third person. Could anybody do an advance care directive for someone who has lost capacity?

Ms NILSSON - No, you need a bit of skill for that. Sorry, how do you mean?

Mr JAENSCH - Knowledge of a person.

CHAIR - That sends up a flag to me. I was concerned that somebody who has lost capacity could have an advance care directive done by somebody else.

Ms NILSSON - Like their spouse, for example, their daughter?

CHAIR - Yes.

Ms NILSSON - But no legal standing.

Ms DAWKINS - No end of life.

Ms NILSSON - It does have legal standing under common law, not under statutory law. That has actually never been challenged.

Ms OGILVIE - It's only a matter of time.

Ms NILSSON - If it's done appropriately it shouldn't be.

Ms SING - One final thing. In terms of the Victorian inquiry there are so many recommendations in there that are worthwhile looking at. I am not suggesting that they need to be adopted, but they are a very good starting point for a whole lot of things.

CHAIR - Thank you all very much; I really appreciate the three of you coming in today. It has been really informative.

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