DYING WITH DIGNITY BILL 2009

Hon. RAY GROOM, CHAIRMAN, <u>Dr HELEN McARDLE</u>, DEPUTY CHAIR, AND <u>Ms CAROLYN WALLACE</u>, STATEWIDE CLINICAL CARE COORDINATOR, SOUTHERN CROSS CARE WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

- **CHAIR** (Mr Finch) Thank you all very much for joining us here today and taking the time to make a submission to us. We are most interested to hear what your team has to say. I will hand over to you for you to make a presentation and we will then follow on with questions.
- **Mr GROOM** Chairman, thank you very much for the chance to add to our written submission that we have made on this bill. We are very much involved in the issues that the bill seeks to address and we think it is appropriate that we should have this opportunity to add to the submission that we have made. On my right is Dr Helen McArdle who is the Deputy Chair of Southern Cross Care and also a medical practitioner. On my left is Carolyn Wallace who is the Statewide Clinical Care Coordinator for Southern Cross Care and also the Director of Nursing at Rosary Gardens, which is our largest nursing home, situated at New Town.

I would like to give a brief overview of Southern Cross Care, and I am sure that members of the committee would have some appreciation of Southern Cross Care and the work that we do. We are a not-for-profit community organisation, very much a Tasmanian organisation. We are the largest aged-care provider in the State. We operate nine retirement villages and seven nursing homes in the south, north and north-west of Tasmania. We are caring for some 1 500 people, or thereabouts, older Tasmanians in our services, which includes community care services where we assist people in their own homes. That is very much an important part of the work that we do and it is a growing part of the services that we provide. We employ 850 people in our State and are therefore one of the larger employers in Tasmania. In fact the TCCI I think a couple of years ago said that we were about number 15 in employment; I would have thought we might be even higher than that, but we are a large employer. We provide care to older Tasmanians regardless of their background, colour, creed, race, cultural background, financial circumstances or religious beliefs. We will accept into our nursing homes anyone regardless of their background.

In our nursing homes and other facilities we seek to provide and create the best possible environment, a cheerful, happy environment for our residents, and we do achieve that. If you go to one of our nursing homes you'd find that is the case. We are very proud of the fact that we have such a happy, cheerful environment. We not only respect the lives of our residents, we also celebrate their lives. We encourage their living. This is fundamental to aged care and this is the approach that I'm sure every aged-care provider

adopts when caring for older citizens. We as an organisation strongly oppose this legislation. It would be Parliament approving the questioning of the value of life and Parliament approving the taking of life, so it is therefore a very serious issue for the Parliament and clearly one of the most important issues that Parliament will ever have to consider, a life or death issue. That is what this committee is considering now and this is what the Parliament will be considering should it proceed to be debated in the Parliament.

We believe it sends out the wrong message for our community, especially for the elderly, the frail, the aged people in our community, when we are questioning the worth of living, of life. This is a very serious matter for the people we care for. It would cause some to question the value of their life, whether they should continue to live. It would raise in the minds of other people in nursing homes when they look at someone else, should that person continue to live. It would also, I am sure, inevitably raise in the minds of some family members should mum or dad continue, or should uncle or aunty continue, and that is a very serious issue for our community. Therefore it would do real damage to this happy and cheerful environment that we create in our nursing homes, this joyful environment where there would be a degree of mistrust felt by people - what is going on? Especially if someone was assisted to die in a particular facility, what would other people in that facility think? People would be looking over their shoulders and wondering, 'Will I be next, or will someone else be next', and they would be very concerned about that. It would place enormous pressure on our staff - Carolyn Wallace will talk about that a little later on - and on medical practitioners - and Helen McArdle will develop that point. We see it as being a very difficult issue for our dedicated staff. As I say, we have 850 of them, and I know there is real concern about what pressure it would place upon them.

This is a life-and-death issue, and it is a bit like capital punishment, which thankfully has been abolished in our country. There is no State or Territory which has capital punishment here. But with capital punishment and all the safeguards that exist, there are still mistakes made. Innocent people have been executed, and that has been quite clearly established. With this process to be endorsed by this bill should it become law, again mistakes can be made. People are human, errors occur, so as a result someone might lose their life wrongly, without genuine consent or a genuine request being made.

I would like to refer to a comment made by Baroness Campbell in the House of Lords only last month when a euthanasia-type bill was debated in the House of Lords. I did refer to this in our submission, and I think it is very important because it talks about the mindset that can flow from a change of the law of this kind. I think this is absolutely critical and fundamental. If this comes in - and it would be the first time in Australia, except for the Northern Territory and that law was overridden by the Commonwealth because the Territory is not a State - it would be the first State in Australia where this law exists. There are very few laws of this kind anywhere in the world. There are a few places - we can go into that if you wish to - but a very few places.

Baroness Campbell, who is herself severely disabled and a member of the House of Lords - and I have referred in my submission to the reference - attended a gathering of 100 disabled people who opposed a euthanasia bill in the United Kingdom and she said in her speech, and I want to quote from it:

'We were there for a very simple reason: because we feared for our lives and the lives of hundreds of other disabled people if the bill were to become law. Our belief was that if the State were to sanction any person to assist another in the ending of that person's life, it would switch the mindset of doctors and those who would help us in this country to thinking this is what we really want, the very people who need every encouragement to live and not to succumb to society's prevalent view that our situation is so tragic, so burdensome, so insufferable, that surely we must want to die. It takes an extraordinary will to rise above such views and many do not, especially when those views are held by our loved ones. That is when it is the hardest.'

I think that is a very important point. Quite a dramatic change to the law would lead to a change in mindset by doctors, by carers, by the community, when people would start question whether a particular life was worth continuing. There might be pain and suffering. It may not fit exactly the conditions required in the bill, but I think it would raise this question - should this person continue? That is a very serious issue for our community because you can look at a whole range of situations - paraplegic, quadriplegic and all sorts of diseases and problems in young people or older people - where people might well question whether it is worthwhile. That is a very serious issue.

In our view, the bill has been poorly drafted. There is no effective opting out. There is a suggestion that an organisation like ours might be able to opt out of being involved. I do not believe that is the case if you look at the bill in detail. When I look at clause 8, for example, I find it very hard to follow. I do not believe it has been well drafted at all and I do not know who has been involved in the drafting of the bill. If you look at clause 22 it says in paragraph (4): 'A heath care provider is not under any duty, whether by contract, statute or other legal requirement, to participate in the provision to a sufferer with assistance under the act.' So there is not a duty. But then 22(2) provides for a complete immunity:

'A professional organisation or association or a health care provider' -

and we would be a health care provider -

'must not subject a person to censure, discipline, suspension, loss of licence, certificate or other authority to practice, loss of privilege, loss of membership or other penalty for anything that, in good faith and without negligence, was done or refused to be done by the person and which may, under this act, lawfully be done or refuse to be done.'

In other words, if such an event occurred in a Southern Cross Care nursing home, it would be very difficult for us to prevent this given the nature of nursing homes. People come in and out all the time. Doctors come in and out all the time. Friends and relatives are in and out all the time. It could happen. If it did happen, there would be no sanction that we could impose. We could not complain to the doctor or those involved. We could not censure anyone. We could not take any action at all because they are given a complete immunity under this legislation as it is proposed. So, in my view and in our view, there is no opting out. We could not say, 'You do not have to be involved'. We could make a policy decision that we would not be involved and it is likely that would

occur. But that would not be effective because we cannot control everyone who comes in and out of our nursing homes. We treat the apartment or the room, the villa or wherever it might be, as the person's own home and they have this freedom. So this is a very hard thing for us to manage as an organisation.

I raise a question and it relates to the right to rescind. What if someone signs the certificate of request and they agree, yes, they want their life to be taken by the medical practitioner or the other person assisting - and that is unclear as to exactly how that would work - and the person, a couple of days later, suffers a stroke. How does the person then rescind that request in writing if they are no longer with proper capacity to make that decision and they are incapacitated as the result of a major stroke? They have on the record that they wish to die. There is a risk there but the medical practitioner will proceed to carry out the wishes expressed before that person became incapacitated. So that recision issue is a very difficult one. I think Carolyn may speak a little later about the involvement of staff. What if someone from the kitchen comes into the room and the person says, 'I do not want go ahead with this'. What happens then? What is the obligation of that person from the kitchen, bringing a meal in? What is the obligation for that person to pass it on to the doctors or whatever? There is nothing in the bill that addresses that particular concern. That relates to clause 12(1) - Right to rescind: 'Notwithstanding anything in this act, a sufferer may rescind a request resistance under this act at any time and in any manner'. So a person can rescind at any time and in any manner. So you could tell one of our staff members, 'I don't want to go ahead with it'. What is that conveyed, what is the obligation and how is that to be handled, because that is a very important issue if there is actually a rescission?

We believe that this committee should direct its energies, its effort and its valuable time to considering palliative care. We see palliative care as the answer but we also recognise that more can be done to improve palliative care in Tasmania. In our regional areas, our small towns and even, on occasions, in our larger cities there is not available the best palliative care that could be made available. This is not just the administration of medication. This is a whole range of matters - counselling, supporting, psychological support, overcoming problems, arranging financial affairs and other affairs. Palliative care is a very broad concept. We can do much better as far as palliative care is concerned. This is the issue that we should direct our energies, efforts and resources to. More can be done as far as that is concerned.

We believe the bill is bad public policy. This is something that was addressed in our last submission that was made back in 1998 before the earlier committee. We had looked at this in some detail. The most fundamental role of a parliament and a government in a democratic society is to care for and protect the people and ensure that the people are safe. Our road safety laws and our criminal laws are all directed at that question of improving the safety of our community - protecting the weak and the vulnerable. The problem with this bill is that, although the people behind it are no doubt well meaning, although there are tragic and difficult cases, the reality is that this will endanger other people within our community. The weak and the vulnerable, the aged and the frail are placed in some degree of danger and jeopardy as a result of this legislation should it become the law in Tasmania. We believe that is bad public policy.

We support the findings of the 1998 committee and in part 7 of our written submission we refer to this. That committee looked at this in a lot of detail. We think it did a very

good job and we support the findings that it handed down, including the need for improved palliative care. That was 1998. In 2009 there is still a need for improved palliative care in our State.

Point 5.29 in the last report in 1998, it said:

'The committee found that the legislation of voluntary euthanasia would pose a serious threat to the more vulnerable members of society and the obligation of the State to protect all its members equally outweighs the individual's freedom to choose voluntary euthanasia.'

We believe that was a very sound finding of the last committee. We would hope that this committee would find against the bill because we believe it does pose dangers. It is unnecessary. We are able to manage, very effectively, with the law as it is at the present time and we are involved directly in this business in a very large way in Tasmania.

Dr McARDLE - I wanted to make a couple of points but I think they are very important points. The first is about the terminology. Throughout the bill it refers to 'a terminal illness'. It does not define a terminal illness beyond that it is terminal. Any neurological illness, renal failure, liver failure, any of those conditions could be classified as a terminal illness if you define it that way.

There is also comment about suffering, profound suffering, pain and distress being caused but once again that is open to interpretation. For one person it may mean something for another person it may mean something quite different.

The bill talks about treatment that is 'unacceptable to the sufferer' but it does not define that. A person with diabetes, which could be a terminal illness, may choose not to use insulin. That may be unacceptable to them and therefore that is open to interpretation and the bill could apply. Likewise with renal failure an individual may not be happy to undergo dialysis, which is a very easily available treatment, but if it is unacceptable to them then they could enact this bill. Those were some comments about terminology.

The other thing is about medical practitioners. There is no mention in the bill that the medical practitioner involved has to be the treating doctor for that patient and there is no mention in the bill that the medical practitioners have to reside in the State, so there is the potential to have fly-in doctors. They may be ones who move around the country doing a similar purpose. They do not have to know the patient, they do not have to know the family, they do not have to understand the circumstances and they can come in and do a job and leave.

There also is potential for a lot of undue pressure being applied to treating doctors. For doctors who care for the patient, care for the family but do not believe that this is the way to go, there could be undue pressure put on them to participate because of their links with that patient.

In the bill there is no comment that if a doctor did not want to be involved and declined to be involved, whether or not it would be their responsibility to find somebody else who would participate. In normal medical practice, if a doctor does not want to prescribe a treatment or undertake a procedure, it is his or her responsibility to find someone else to

take that on. That is not mentioned in here and I am not sure if that would be a requirement but that would likewise put doctors in the very difficult position of having to participate.

Finally, I would like to re-emphasise the importance of palliative care and the fact that we should have a very good palliative care service. I think we have a reasonable one in the south but I am not so sure about elsewhere in the State or in the country. If we had a very good palliative care service then most of the concerns expressed by patients leading to a bill of this form would be overcome.

CHAIR - Thank you.

Ms WALLACE - I would like to make a couple of points from a residential aged care facility perspective to do with the logistics if these situations arose.

First of all with regard to clause 8(1)(p) where it talks about providing assistance to the doctor who is assisting the sufferer, who is expected to provide that assistance? Is the doctor going to bring someone to do that or will the facility staff be expected to render some assistance, whatever that may be, to this doctor doing the provision of his assistance to the sufferer and until death occurs? It may be some time between the assistance being provided and death occurring.

The other issue relates to 11(1) about the expectation if the sufferer is unable to sign the certificate of request for themselves. Will facility staff be called upon to do that? Will those staff have any responsibility to ascertain any of the circumstances or facts around it, other than the fact they are asked to sign this for Mr Smith? There is a reasonable likelihood that there will be pressure applied by the attending doctors and the family members to get somebody to sign the request if the sufferer, for whatever reason, is unable to sign. I refer back to Dr McArdle's comment. Because there is nothing in the bill about it being a regular or treating doctor, you could have a scenario in an aged-care facility where three medical practitioners arrived in the evening. You could assume that they were just three people coming to visit that particular resident, make their assessment, and then 'Hey, Mary the carer, come and sign this for the person', and the whole thing is done. There seems very poor accountability around that.

The other concern I had was around due process. If a care provider had some concerns around the due process with regard to consent, signing the certificate of request, assessment of competence, assessment for the sufferer, to whom should you report those concerns? There is no mention at all. At the end, if the expectation is that you report it to the coroner, it is a bit late.

The next question I have that doesn't seem to be answered - and Mr Groom talked about it - is about the sufferer choosing to rescind their request. To whom do they do that? To the initiating doctor or any of the three doctors involved? How should it happen? How should you develop an evidence trail that is has happened? What is to stop somebody going around and saying, 'These 10 people have rescinded'? How do you prove that may have happened? Is the sufferer still competent to rescind? There is nothing to do that. The person to whom it is reported, as Mr Groom said, could be the kitchen lady delivering their breakfast; what is the responsibility of that staff member? What is the process they should follow to do that? What if the kitchen person doesn't really

understand what the sufferer is saying to them when they're choosing to rescind it and they do nothing? It may well then go ahead but the person has rescinded their consent.

Clause 16 is about the responsibilities of aged-care facilities to report any assisted death to the coroner as a reportable death. Currently if there is what is deemed to a reportable death, the facility refers it to the coroner. Is there still that responsibility of the facilities if there was an assisted death? What if the facility is expected to provide relevant records to the coroner, as is the case now, and what would happen if our assessments of the resident were contradictory to those of the assessing doctors in this process? That is probably particularly the case if there is no requirement for it to be regular treating doctors.

There is really no consideration of other residents of the care facilities. Residential facilities are a community and it places unwanted pressure on them. The family of the sufferer may also, through discussions, place unwanted, unnecessary pressures on other members of that residential community.

- **Mr BEST** I have some difficulties with the legislation in the context of the message it promotes. We hear from time to time random cases where the husband has assisted the wife who has suffered, or vice versa, and then they are charged. Do you think those people should be charged in those circumstances?
- **Mr GROOM** I think it is dangerous to make a judgment that people shouldn't be charged generally in those circumstances because it could lead to quite difficult situations. For example, a husband bashing a wife and so on and then arguing it was for certain reasons. It would depend on the circumstances. There is a discretion as to whether someone is ultimately charged and prosecuted and that discretion has to be properly exercised. I think it would be dangerous to make a judgment that in those circumstances such a person should not be charged; it would depend upon the facts.
- **Mr BEST** Do you think maybe there's an argument that should be explored a bit further in those circumstances where there could be a genuine issue perhaps, or genuine background, that maybe there should be some who are treated a little differently? I am not saying it should not be investigated.
- **Mr GROOM** No. You would hope that the current process is sufficient to look at the facts, determine the facts and decide whether it's an appropriate case for a prosecution, but again we have to protect the community and people have to be protected in that situation. Sometimes abuse occurs and excuses are made when someone dies, so I think it's a very difficult issue.
- **Mr BEST** Thank you. You mentioned that there are I think roughly 1 500 people that you care for throughout Tasmania. This question is to you, Ray, or the panel, whichever way. Are you aware of any clients or people that you have been looking after who have asked for any assistance to access death, basically, because of their situation and who have not been able to have that?
- **Mr GROOM** Perhaps Carolyn Wallace, who is very much at the coalface of these things, a very experienced registered nurse, director of nursing in charge of a major facility, may address that. Carolyn may talk about palliative care, too.

- **Ms WALLACE** I have been in aged care for nearly 14 years, and have never been directly asked by a resident. Their question often comes from their family and friends, and that is talked about in some of the papers by the palliative care specialists; it's referenced in quite a number of the papers that it's the family and friends who find the watching of the sufferer that's the problem. I don't think that's enough reason to actively terminate somebody's life just because other people find it uncomfortable. That is also pointing to an inadequacy in the amount of palliative care support that is available. It's not just about giving medications and things to the sufferer. You have to look at the sufferer as a group of individuals, and that includes their family and friends who also need some proper support.
- **Mr BEST** Just two more questions and then I'll share it around a bit. Just on that, you obviously do share that view about peer group pressure that could occur if there was legislation such as this.
- Ms WALLACE Absolutely.
- **Mr BEST** How would you see it potentially happening, then? Would somebody be filling up a space or causing stress to others?
- **Ms WALLACE** If I could use just a scenario, if you have a person who is in residential care, there's subtle pressure by their family relating to the fees for residential care. 'If you weren't here, Mum, we could do whatever with that'. It's not direct pressure, and the family members would probably be horrified to think that it was direct pressure, but it's this indirect sort of stuff that makes the person in the bed, who is my prime concern, feel as though they're a burden.
- **Mr BEST** Finally then, we heard recently about Mr Rossiter's case in the Western Australian court. He was a paraplegic and won the case not to be fed. Mr Groom, you have a very strong legal and political background and knowledge. We heard from witnesses about the Netherlands and the fact that it was a change in the law that led to parliament then changing its position on euthanasia. Is there any comment you'd like to make about that, about things that might emerge in the court system and how that might cause Parliament to think?
- **Mr GROOM** There is a distinction between the positive proactive act of bringing about the death of someone in a very intentional way and palliative care. We certainly recognise, as we made clear in this submission and our previous submission, that you don't take artificial action against the wishes of the person to prolong life unreasonably. That is wrong. You have to respect the person's wishes. In palliative care medications can be administered to relieve the pain and so on; the intention is to relieve the pain. There is no obligation legally or in any other sense to continue life indefinitely.

Regarding the person in Western Australia that you referred to - a quadriplegic person suffering - this was a decision by the court which is quite consistent with the law generally in Australia, it seems to me. The law is very reasonable if it is properly applied in Australia at the present time. People in aged care like Carolyn cope very well and the people are able to be managed very well. The title of the bill, 'Dying With Dignity', is, in a sense, trying to capture that dignity. This is one bill that is claiming dying with dignity. Most of the deaths that occur are with great dignity, with wonderful support from families, friends and so on. This is dignified death. In our facilities, this occurs: dignified death. You do not need a bill. One would argue whether an official death of this kind - an injection, signing certificates and all that sort of thing in a very official way - is dying with dignity. It does occur now.

- **Mr GAFFNEY** Mr Groom, regardless of the bill's drafting or its title, you would be fundamentally against the intent of the bill anyway?
- Mr GROOM Yes. Our comments do highlight some difficulties, no matter what sort of bill it was, that would be present almost inevitably. We, as an aged-care provider and we speak as an aged-care provider see this as fundamentally striking at the heart of the work that we do. That is the point. We are caring for aged, frail, often very ill people. We encourage their living; we promote their living; we support their living. So this bill is directly against that basic approach that we have.
- **Mr GAFFNEY -** I appreciate that, and I know there is only a minimal percentage of people who are in agony, and that is their perceived agony, whether it is ours or not. How do you in a compassionate society accept that that is just I am not saying 'bad luck' but for our legislation at the moment, that person is going to die in pain and cannot be assisted?
- **Dr McARDLE** Palliative care has come a huge way in the last 10 or 15 years. The medications available have changed and the combinations of medications have changed. So instead of just using, say, opiates where people are bombed out, now there is often a mixture of a whole variety of different medications. In general, pain can be managed. If they are still in a lot of pain then the medications can be increased, and if they are still in a lot of pain the medications can be increased again. Because of the specialty of palliative care and the advances that have been made in looking at the combinations and so on, pain in general can be managed to an acceptable level. It may mean that because of the amount of medication, life is shortened somewhat. But the patient the individual is the one that has to be managed, and their pain is very important if they are in agony.
- **Mr GAFFNEY** I know that some of your colleagues are quite comfortable with the fact that there can be PAS, because that has been stated not a lot of them, but there are some. If palliative care specialists were trained in general anaesthetics for those people who were in pain, would that have any advantages?
- **Dr McARDLE -** I am not exactly sure what you are asking but are you saying should palliative care physicians be anaesthetists?
- Mr GAFFNEY Yes, or have that -
- **Dr McARDLE -** I would say no, because you have anaesthetists and you have palliative care physicians. An anaesthetist will just put someone to sleep. What is the end result of being put to sleep? I think it is managing the total body, the total person and their symptoms. It may be pain is their symptom; it may be shortness of breath; it may be anxiety. There is the full body that has to be treated, with different medications for different symptoms. Anaesthetics are short lasting and eventually the person will wake up.

- **Mr GAFFNEY** In a certain case, Mr Cordover, who was of sound mind, was in pain and agony and wanted not to be here. The view of the AMA is that they would not be involved with that or would not accept that?
- **Dr McARDLE** I am not familiar with the case so I cannot answer specifically and I cannot speak on behalf of the AMA. As Ray said, we are here talking as an aged-care provider, looking at our particular group of patients. We do not tend to have younger disabled or younger palliative patients. Our age group start from 65 upwards.
- **Ms FORREST** Ray, you made the comment that there are a lot of issues, as you see it, with the bill, referring to a number of different sections. Do you believe that it could be amended in such a way that it could address those issues adequately?
- **Mr GROOM** Not to our satisfaction, no. I answered that question earlier, I think. We fundamentally are opposed to this concept of the Parliament approving the taking of life.
- **Ms FORREST** In spite of that, the decision of the Parliament may be to support the bill and if that happens, then you have a bill that you will have to work with, at the end of the day. I do not know what the outcome will be and I would not even like to predict. But what I am saying is, if that were to be the case, then there is the committee phase, obviously, of the bill where it can be amended. Do you think there are ways it could be amended to meet those concerns that you have if the bill is to be passed and that is the decision of the Parliament? Do you think it could be dealt with in that way?
- **Mr GROOM** Again, I make the point that we are opposed to the taking of life. The bill is badly drafted. The bill needs to be improved. I am told that there may be even changes in the wind already to the bill in other words, it may not be the final bill that goes to the Parliament. With all the improvements, it still would be the taking of life, approved by the Parliament, which is unique. We would be the only State in Australia where the Parliament has approved such a move. It would set the wrong scene and send the wrong message and there would be all the problems that we have already talked about.

An ideal bill, very well drafted by a parliamentary draftsman, would still not satisfy us. But in making our comments about particular issues in the bill, it does highlight concerns about the fundamental issue.

- **Ms FORREST** There were a couple of issues that were raised in relation to the medical side of it. Mr Gaffney mentioned a point about the anaesthetists. I have spent a lot of time talking with palliative care specialists myself and it would seem that the big lack in that area is the education of GPs. The GPs are involved in nursing homes. With the recent advances that you talked about in palliative care, it seems that there is not a great deal of knowledge out there in the general practitioner world, as well as in the broader population. So, as far as that goes, is that the most appropriate approach or what is the way forward here if you say that palliative care does not relieve suffering for some people? A lot of people have seen deaths in the past where it has not provided relief. How do we address that?
- **Dr McARDLE** I think you are quite right. You have the specialist palliative care physicians who have extensive knowledge but there are only a few of those and even in the south there are still only a few of those, although it is much better than it was a few

years ago, and then you have all the GPs. The GPs may only deal with a palliative patient every few months and so they cannot hold all that specialist knowledge. So I think really what is required is more specialists, more GPs, I suppose, with a special interest who can develop. They may not want to train to the specialist level but they can develop their skills so that they have a bit more than the average. Also, more specialist palliative care nurses who can provide a lot of guidance to the GPs and support the GPs are needed. I think if the effort was put in there, that would improve death for most people because GPs, if they only deal with a palliative patient every three or four months, cannot keep up that level of knowledge and skills and know the special little things that can be done. So I think it is access to specialists but also access to specialist nurses and then probably a pool of GPs who develop a special interest in that area, as happens in a number of other areas in general practice.

- **Ms O'CONNOR** Mr Groom, you said earlier that palliative care is a very broad concept. We heard at the last hearings in Launceston from Dr McGushan who is a Catholic doctor at the Calvary Hospital and he talked about those instances where there is a terminally ill patient who is in a profound state of suffering, where a palliative medicine is administered to relieve pain, out of compassion, but the effect is to shorten life by a few hours or even a few days. I am trying to glean the difference between that palliative care treatment where a doctor administers a drug in the full knowledge that the medicine will end the sufferer's life, and where the patient himself or herself requests the medicine and the assistance?
- **Mr GROOM** It is the intention, which I think may have been said before, but it is true. The fundamental purpose is to provide relief in the first instance, relief from suffering through palliative care, and in some situations the medication administered may hasten death by a day or two, an hour or two, whatever it might be, but the objective is to relieve the pain and suffering of the individual. That is the purpose. In the second case that is, this bill the intention plainly is to cause the death of the individual in certain circumstances to bring about the death. That is the difference. On palliative care, Carolyn Wallace is very much involved in this in a nursing home environment. Do you wish to add to this?
- **Ms O'CONNOR** I guess my question would be, Carolyn, what to your mind is the difference between an act of palliative care that ends a sufferer's life prematurely and a situation where a sufferer has requested, acting out of their own desire for personal autonomy, assistance to end their life?
- Ms WALLACE I think when you are talking about acting, palliative care is about managing someone's symptoms, and they are not all medical or need medication to resolve. There is a whole person there that has a whole range of things that need to be sorted through and resolved and managed, and the person is not just the one individual in the bed. They also come with a network of people. I think euthanasia is in another totally different basket and it is an active intervention, the sole purpose of which is just to end that person's life. I think palliative care and euthanasia are two quite different concepts.
- Ms O'CONNOR You acknowledge here that we are talking about voluntary euthanasia, where the sufferer requests the assistance. It is not an active euthanasia where someone is put out of their misery, which in some ways it could be argued that palliative care

becomes, because it is an act of involuntary euthanasia, because if you have a person there who is suffering terribly and the doctor or the administering medical professional makes a choice to give a certain type of medication without the patient's consent because they are not conscious, and it relieves their suffering but ends their life, that is an act of involuntary euthanasia, isn't it?

Ms WALLACE - No.

Ms O'CONNOR - Why not?

- **Ms WALLACE** I think if someone is unconscious, they have other people who are responsible for making decisions on their behalf; they have families and friends. I think palliative care and euthanasia are in two quite separate baskets.
- **Ms O'CONNOR** Dr McArdle, I am interested in how the law as it currently stands and Mr Best was talking about the case of Mr Rossiter in Western Australia - discriminates against people with physical disabilities in that if, for example, I am suffering a terminal illness, I can choose to end my own life because it is not illegal to attempt or commit suicide in Australia today, but if I am a physically disabled person who is suffering a terminal illness, I do not have that choice of relieving my own suffering. How do you respond to what is inherently a discrimination against people with disabilities who may be suffering from a terminal illness?
- **Dr McARDLE** I think if we use that example to explain it, he obviously could not actively commit suicide, but what he could do is choose not to have treatment, so he chose not to be fed, knowing that the outcome would be death. People who are severely disabled are going to be prone to infections, largely chest infections but also urinary tract infection and if they should acquire an infection, they can choose not to be treated and they will often choose not be treated, knowing that the outcome will be death.
- **Ms O'CONNOR** But do you accept that the law does discriminate against people with disabilities, physical disabilities in this instance?
- **Mr GROOM** What do you mean by discriminate? There could be all sorts of situations where someone is a young, disabled person and they're not happy with their life and they want to take to their life. Is that discrimination not to allow them to take their life?
- **Ms O'CONNOR** No, what I mean is that if a person has a physical disability and they are suffering from a terminal illness, they can't take matters into their own hands in the same way that an able-bodied person can; they simply cannot do it, there is no capacity. So they ask someone else to help them end their life, which makes that person complicit, with no protection under the law.
- **Mr GROOM** I'm looking at the logical basis of your question, which seems to be choice. Where does choice end? We wish to encourage young people to continue to live, enjoy life, and choice is fundamental. It seems to be fundamental to your question. Do you go beyond someone who is suffering a terminal illness? You might be discriminating against a disabled person because they're not suffering a terminal illness as such, that is discrimination; they should have the choice too. I think that is fundamentally wrong. We have to encourage living and celebrate it.

Ms O'CONNOR - Of course, no-one is arguing with that.

Mr GROOM - But I would question the logic of it.

We urge the committee to consider our submission, as no doubt it will. It is an important issue for our community and we believe that the committee should find against the bill, consistent with the decision taken in 1998 by a similar committee. I think it was a committee of the House of Assembly rather than a joint committee on that occasion. That had a long and exhaustive inquiry and lots of views were expressed. We are very grateful the Parliament has agreed to put this matter before this committee so that we have a chance to express our thoughts.

CHAIR - Thank you, we appreciate your time.

THE WITNESSES WITHDREW.

THE VERY REVEREND RICHARD HUMPHREY WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

- **CHAIR** (Mr Finch) Thank you for coming along. We will ask you to give us a presentation and then we will ask questions.
- **Rev. HUMPHREY** I'm here speaking both for myself, the Dean of the Hobart, and also as the Deputy Vicar-General of the Anglican Diocese of Tasmania. Therefore I will talk to both my submission and that of the Anglican Diocese.

The Anglican Diocese submission was essentially the submission that was made in the 1997 process and we want to stand by the recommendations that were made in that submission - that is, that palliative care services be strengthened; provision of spiritual and emotional counselling for the terminally ill; education and training for professionals in areas of palliative care; special attention be given to rural areas; and that the legal status quo be preserved in Tasmania. In one sense that picks up some of the questions that were asked of the previous people.

From our point of view, none of the arguments have changed since the last time this was around. The only thing that has improved is palliative care and so all the arguments from 1997 still stand.

From a theological point of view - and here I speak on behalf of the Bishop, but I agree with him, as I promised to do - it is God who gives life and God who takes it away. We are fearfully and wonderfully made in the image of our creator. It is not for humans to take life. As a gift from God, it is a sacred trust and is not to be taken by human hand. The dangers of euthanasia have been rehearsed, and the need for proper care for the dying, for palliative care. As a Christian community and a Christian church, we want to encourage compassion and care in practical help rather than ending life. Not only do we hold that life is special and that God has created us wonderfully, we also believe in the sinfulness of humanity. Speaking as someone who has worked in pastoral ministry for 13 years around people dying, I have seen some truly appalling things happen. I do not mean all the time, but I have seen people behave in truly astounding ways about wills - 'Can't we deal with grandma quickly?', and so on. I am obviously not saying that would happen in every case but it does happen. If this bill is made legal, it will open the doors, I believe, for abuse in that way.

I guess also the Bible does put forward a different view of suffering, that suffering is not something to be necessarily run away from. Whilst not wishing to glorify or recommend it, it does give opportunities for growth and transformation. I am sure that Dr Paul Dunne would have already argued or will be arguing that case in another place. That does need to be balanced with the position of Jesus of showing healing and compassion as well.

We are aware that to make a theological argument will not necessarily win the day at all but we do wish to have those things put. In an attempt to create a secular argument, I briefly argued that this bill is unnecessary because we have wonderful palliative care facilities. Nothing has changed since the last time a bill like it was rejected except that palliative care has become better.

One of the statistics seems to be that although the general public is very favourable towards the idea of euthanasia, for those for whom it directly affects - those who are terminally ill - the percentage who wish to do this is very, very small, so I believe the bill is unnecessary. Secondly, I believe it is unfortunate and this is the argument that has always been used. For instance, the House of Lords report said this:

'The value of the Netherlands experience is not in the establishment of a right to die a dignified and humane death. The value is providing an example of the perils of active voluntary euthanasia as a whole, and for each vulnerable person within that society a right to die, once accepted, too easily becomes a duty to die or an excuse to kill. Euthanasia in the Netherlands is a notorious example of how unprincipled humanitarian intentions produce chaos in law, medicine and health care.'

The Archbishop of Canterbury made a submission to the House of Lords and also pointed out 'that if we specify conditions under which life may be ended, that is to say that certain kinds of human life are not worth living, as soon as that publicly is granted we put at risk the security of all who experience such conditions'. The findings of the similar committee to this in 1998 pointed out the same thing:

'The committee found that the legislation of voluntary euthanasia would pose a serious threat to the more vulnerable members of society and the obligation of the State to protect all its members equally outweighs the individual's freedom to choose voluntary euthanasia.'

I have lost my quote from the 1993 House of Lords document, which basically said the same thing. So when committees have dealt with this, that is what it has always come back to, the dangers that putting forward a bill of this nature creates. It is unnecessary, it is unfortunate and I believe again - I may be coming back to theology - it is untested because it runs on the assumption that dead is better than living with pain. I would like to know the basis for such a statement.

It seems to me that that is a theological argument whether you like it or not. For me, I would follow somebody who has been through it but that particularly may be going to a theological argument. So that's a very short summary of my and the diocese submission.

- **CHAIR** With your parishioners, do you have much of a discussion about euthanasia and dying with dignity? Is there talk amongst members, particularly older members?
- **Rev. HUMPHREY** Sure. We've been encouraging debate on this matter, and we have had a number of things at the cathedral where ideas about euthanasia have been promoted. In my conversations, the elderly have been uniformly against it. They haven't necessarily agreed with all my arguments as to why I am against it, but it has fallen down to that idea that compassion means caring for the person - in fact the kinds of arguments that the palliative care specialists were saying before - and the value of life.

The other thing that we do talk about, which has regularly come out, is the pain that they feel as they watch their people suffering, as they watch one of their loved ones suffer with Alzheimer's or with somebody whose cognitive abilities have degenerated a lot.

There is a great deal of suffering at that, but they recognise that it's their suffering rather than the suffering of the person who was there.

As somebody who has visited nursing homes for much of my pastoral career, there would be many that I would have visited who from the outside may have seemed to be a life that's not worth living, but for those people that I meet, as I pray with them and as I see them smiling as I talk about things, it's life to them and I'd hate to put their life in danger by passing a bill such as this.

- **Ms O'CONNOR** Your statement about God who gives life and God who takes it away, what is your view on the moral issue of a palliative care doctor who administers a medicine to relieve symptoms but in the full knowledge that life will be shortened? Is not that doctor taking a life away, effectively, although the intent is to relieve pain and suffering?
- **Rev. HUMPHREY** I would argue exactly what was argued before; the issue there is intent. The intent is to deal with the suffering; the intent is not to kill the patient. That may be a consequence.
- **Ms O'CONNOR** How do you separate them if the intent is to relieve but the knowledge of the medical professional is that life will be shortened by hours or even days?
- **Rev. HUMPHREY** But the knowledge of any health professional and anyone is that life will end at some stage. The issue is not whether you are trying to kill the person; the issue is are you trying to heal the person or to end their pain. For me the distinction is quite clear, that of intention. Intention is something that's taken into account in law, and many of our acts are based on the intent of that act. If the intent is to reduce suffering, that's one thing, and there may be a consequence from that. But if the intent is purely to kill, which is what active euthanasia is, it's a deliberate decision to kill the person.
- Ms O'CONNOR But is not the intent with voluntary euthanasia to end suffering?
- **Rev. HUMPHREY** It's to kill the person, which is believed to end the suffering.
- **Ms O'CONNOR** I can't really see how you can say there's a real difference because the intent for the sufferer of a terminal illness in requesting assistance under this bill is to end their suffering.
- **Rev. HUMPHREY** I would say that good palliative care would be the way to deal with and manage their suffering.
- **Ms O'CONNOR** But do you acknowledge that for some people who suffer from terminal illness, palliative care does not provide the solution?
- **Rev. HUMPHREY** I am not a medical doctor so I am not sure that I am competent and capable to answer that question. From my reading of data and from speaking to those in the health arena, that percentage is extremely small.
- Ms O'CONNOR Okay. I will just go to a theological question here, I am really interested in this. When you talk about the basic premise of the bill being untested - that is that

profound suffering is better than death but that's an untested proposition. You are a religious man who presumably believes in an afterlife, in heaven.

Rev. HUMPHREY - Yes.

- Ms O'CONNOR How can you say that is not tested based on your philosophy, your theological belief?
- **Rev. HUMPHREY -** I can argue that it is tested. But in a secular argument, you cannot argue that it is tested. I think it is perfectly tested historically in the life, death and resurrection of Jesus Christ. I thank you for asking that question so I can put his name on the record. For me, in the resurrection there is the proof of a better world to come and such things. But I am simply arguing on a secular basis. It is an untested proposition, and untestable, I would argue, on a secular proposition. That is my point.

Ms O'CONNOR - Thank you.

- **Ms FORREST -** A matter that was raised in previous submissions was the issue of the broad support in the community for the concept of physician-assisted suicide and other forms of euthanasia. Your Catholic colleagues informed us they got a bit of a razz for being so out there saying, 'No, no, no. We oppose it'. The ensuing discussion found that a lot of their parishioners understood that things such as refusing treatment, withdrawing futile treatment or not commencing treatment that is deemed to be futile was included in the same box. Is that your experience? Do your people actually understand what we are talking about here?
- **Rev. HUMPHREY -** I hope so. We had Christopher Newell as part of the congregation of the cathedral for many years. He made a very substantial submission to the last committee, which I believe has been put in by his father again for this process. So the ethical level of debate at the cathedral is much higher than you would get at your average church. So in terms of the cathedral the answer would be no, but in talking with people pastorally at the bed side, when these things have come up we have talked about the difference in ethics between refusing medical treatment and actually actively seeking to end somebody's life. So that tends to come up after a car accident or something like that with somebody on life-support. People have asked me and they have tended to lump euthanasia in with not providing medical assistance.
- **Ms FORREST** The same could be said of even people in their later years who get pneumonia and potentially refuse treatment or dialysis for renal failure or whatever. Do you suggest that a lot of people, when they are asked the question, 'Do you support voluntary euthanasia?', throw all of those things in the same basket and, hence, potentially the high support for the concept?
- **Rev. HUMPHREY -** There may be some of that. I tend to think it is mainly because we see the suffering of people. Again, from somebody who has done some truly horrendous pastoral visits to people, you think, 'I would not want that to happen to me'. So you ask me at that point: would I support terminating that life? On one level I would go, 'Yes'. But that is not actually about that person. That is about my reaction to the situation that that person is in. I think that has a lot to do with the high level of support.

Ms FORREST - So your personal experience of death in other situations?

- **Rev. HUMPHREY -** Or seeing somebody, and we assume that that life is not worth living. The danger in that popular mentality is that, as soon as we start to say a life that looks like that is not worth living, what does that mean about this person over here who may be also experiencing the same thing? We are making a blanket thing that such life is not worth living. That, for me, is a problem with it. If somebody wants to support the dignity of life and the certain specialness of life, that is the trouble I have with that. Popular opinions are a dangerous thing.
- Ms FORREST This was raised by one of your Catholics colleagues a parishioner who -
- **Rev. HUMPHREY** I had better ring Archbishop Doyle and check that I am all right to answer on his behalf. I did not realise I was answering for both bishops.

Laughter.

- **Ms FORREST** No, this was raised by this person with a religious background, though not involved in the leadership of the church or anything like that. A mere parishioner, he called himself. He said he felt that this bill was quite discriminatory because it discriminated against a whole range of people who may be suffering intolerably from mental illness, though not a terminal illness. They are people who have dementia, who are incompetent and do not have the capacity to make a decision about that very fact. His argument was that it should be rejected on the basis that is it discriminatory. Do you have a view on that?
- **Rev. HUMPHREY** I am not quite sure I follow his logic. It seems to me an unusual argument to make because I assume he is saying that if somebody is not mentally competent to make that decision, then the bill does not apply for them.
- Ms FORREST They do not fit the bill for whatever reason.
- **Rev. HUMPHREY** For me that is a dangerous argument to make because I would be fundamentally opposed to the bill because of its intention to kill people. I would not want to see that the way to solve that is to broaden the scope of the bill and therefore we solve the problem.
- Ms FORREST He was suggesting that the obvious thing is to chuck the whole thing out.
- **Rev. HUMPHREY** His argument could be flipped on its head. There are euthanasia campaigners, I think Philip Nitschke made the point, that if anybody wishes to end their life we should allow it to be assisted. That, to me, is the danger of where we go once we start to make legislation on this matter. It becomes a subjective matter; if I think my life is not worth living therefore I should have the right to do it. I know that is not the intent of the bill but as soon as you open up that path then that is the danger of doing this.
- **Mrs BUTLER** Paul Dunne argued in the *Mercury* that the possibilities of growth, transformation and forgiveness are not able be taken if life is ended prematurely. Would you like to speak further to that?

Rev. HUMPHREY - Whilst I made some comments about some horrible things that happen around bedsides, you also see some truly wonderful things that happen around bedsides, and through funeral processes as people start to talk about things that have been there for a long time and family matters are dealt with. Again, I am not arguing that would happen in every opportunity, but if mum suddenly decided to take herself off to the local clinic and finish it all off one day, that opportunity for dealing with some issues that might be there in the family are not there. I appreciate it is a double-sided thing. I am arguing that people are bad and also that there are opportunities for good to come out of it.

I remember a guy called Jim Keats who was dying and there were probably about 23 people in the room. It was a wonderful thing as we were waiting with him as his time came. People were sharing stories and realising things that they had done wrong and were able to speak to him. That was a beautiful time as we waited for his time to come to an end. So those kinds of things can be there. Jim obviously was no longer competent to speak but there will be other opportunities where, in that person's suffering, they may be able to share things with their family which are really important and which would be denied if their life were to be terminated early. I am sure Paul will be able argue more forcefully for his own position, but I found that quite striking and fitted with my own pastoral experience in hospitals and nursing homes.

- **Mr BEST** I want to preface this by saying I have concerns about the message that the legislation sends. You mentioned earlier about the chaos and turmoil and mess in the Netherlands. What is the position of your church in the Netherlands?
- **Rev. HUMPHREY** We do not have a church in the Netherlands. There is a diocese of Europe, which is focused in Belgium. Our reaction to the legislation in the Netherlands would be to oppose the current legal status quo in the Netherlands, as it would be in Oregon and other places around the world where similar legislation is. However, I am not competent to argue what an official representative of the diocese of Europe would argue in that case.
- **Mr BEST** I think it is a very good point you make about how people would feel in the context that if someone was suffering from something and facing death and were told that most people in this circumstance would choose an assisted death. I could see how that could have some bearing. You mentioned that there are some discussions that you have with elderly people in your community; they do not necessarily agree with your position. Do you want to highlight some of those?
- **Rev. HUMPHREY** They would not agree with all my arguments for why I think it is bad, so not all of them would like my last argument about untested. Some thought that was a little bleak. Some struggle with the idea of compassion, and that is a difficult one when somebody is suffering and is in pain and they have somebody in their house who is in that circumstance these are often elderly people and one of the reasons I went back and rewrote my submission was that it was felt that some of the ways I was arguing sounded as though I did not have enough compassion. One of the things I want to try to argue is that by arguing individual cases, you end up not showing compassion to a whole class of people who may fit into the same situation but who may then have pressure applied to them, 'Stop being a problem'.

Mr BEST - So it is people who might happen to have a different view to yourself?

- **Rev. HUMPHREY** Interestingly, the secular argument seemed to work better than some of my theological ones, but we will get there.
- **Mr BEST** You mentioned you get around a lot of the aged-care facilities and obviously you have quite a lot of contact being in your position. Have you heard stories of people who have been in situations where they are suffering and they have begged for assistance for death, basically?
- **Rev. HUMPHREY** It has never happened to me. I have had very bewildering conversations with people and it has only ever been at the level of, 'Help me!' What that entails has not been spelt out but normally that has meant better health care or palliative care and so with somebody who has been in that situation, I have been back and seen them later and they have been calm and I have been able to have a better visit.

I need to say I have only been back in Tasmania for five months so I do not have a great deal of experience in Tasmania but in New South Wales in my former parish generally most of the things that I saw, both in hospitals and in aged-care facilities, was that people were given a very dignified death, through the process of palliative care, of being able to say goodbye to their families and have been well looked after, and that to me would be the way that we should go.

- **Mr GAFFNEY** It has been stated that nothing has changed much in the last 10 years regarding this issue except better palliative care, and that is good. However, it is obvious that the number within the church has suffered a decrease, according to some statistics. The church has faced many issues where their views have changed over time, whether it be on premarital sex or abortion, and even now we have a submission from a Christians for Euthanasia group. How does the church accept and involve the Christian Group for Euthanasia, which is fundamentally opposed to the church's view on this matter? How do you work that, because you do not want to lose people from your congregation?
- **Rev. HUMPHREY** Sure. I guess I would want to question some things behind that answer. I am not quite sure what the decline in the size of the church has to do with any changes in the legal set-up about euthanasia.

In terms of how we deal with other people, I am aware that people will argue from a different point of view and I am aware of this group; unfortunately I have not had time to really chase up their arguments. In general, the one thing I remember is that it is based on autonomy and individual choice and the idea of compassion. My concern would be to argue that in the end this opens up an uncompassionate society. I do not ask anybody 'Are you for or against?' That is not the issue on which we have fellowship; we have fellowship around what Jesus has done for us and I would want to celebrate that together. That may mean that we have all sorts of arguments - and I'm not sure that the church has changed its mind, for instance, on pre-marital sex and abortion; we may not say it so loudly but I think we are still pretty clear on what we think about those things - but that again is not central to what we're doing as a community. What I'd want to be arguing is on the basis of the type of life that we are encouraged to have in the Scriptures and in Jesus. I would be wanting to encourage people to continue to think these things through.

People's minds may change but there will always be differences of opinion, and that is okay. That does not particularly worry me.

- **Ms O'CONNOR** You were saying before that when you show compassion for an individual, in this instance on this topic, you're potentially not showing compassion for the wider community and I think that is the slippery-slope argument but do you agree that there's a risk here of showing dispassion for the individual sufferer?
- **Rev. HUMPHREY** No, I would hope not. Through palliative care and proper medical treatment, in almost all circumstances the pain can be managed.

Ms O'CONNOR - Almost?

- Rev. HUMPHREY Well, almost, but -
- **Ms O'CONNOR** What do you do for that person who is in agony and for whom palliative care is not providing relief? How do you express compassion towards that person?
- **Rev. HUMPHREY** That may need to be managed through the individual circumstances, but to open up the environment, what do you then do to the person who is in exactly the same situation but who doesn't want their life to end? As soon as you open that up for that person, the pressure is on this other person to have their life terminated because, 'You're being such a drain on us, you're using up valuable medical facilities'. If you say this person does have the right, then the pressure on that person to take the same decision is increased enormously. If we say we're showing compassion to them by legislating, we are then not showing compassion to this person by opening them up to the possibility that we have a medical system that is set up to kill them rather than care for them. That is how I would answer that question.
- CHAIR Thank you. Is there anything you would like to say in a closing statement?
- **Rev. HUMPHREY** No. This process was dealt with on an exhaustive basis in 1996, 1997 and 1998 and I want to continue to argue that we should continue the legal status quo in Tasmania. Please stick by the recommendations of the previous report. I encourage the recommendations of the Anglican Diocese.

THE WITNESS WITHDREW.

<u>Ms DEBRA CERASA</u> AND <u>Professor TRACEY McDONALD</u>, ROYAL COLLEGE OF NURSING AUSTRALIA, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

- **CHAIR** (Mr Finch) Thank you very much, ladies, for making the trip from Canberra and Sydney to give evidence to us today. We will give you as much time as we are able to enable you to present your case. I presume you both have a presentation prepared that you would like to make us?
- **Ms CERASA** I am currently the Chief Executive Officer of the Royal College of Nursing Australia - RCNA. RCNA is a professional peak organisation, not-for-profit, representing the professional voice of nurses across the diverse profession of nursing in Australia. We also have members who are midwives.

I would like to make an opening statement in regard to a few things to support our position statement that we forwarded to you, but Tracey is certainly one of our Fellows of the Royal College of Nursing Australia who is a highly-respected clinician and nurse in the area of clinical care, especially in aged care, so some of the clinical aspects I am going to leave to her to answer your questions. But I just want to reiterate a couple of comments, if I may.

We presented a position statement, which is RCNA's current position statement, and I think it lays out the sensitivity and the difficulty in having a strong stance when you are representing a profession on such a subject. I would like to draw attention to a couple of points, and one is that RCNA believes that nurses have a professional responsibility to stay reliably informed about the ethical, legal, cultural and clinical implications of voluntary euthanasia/assisted suicide. We also believe that nurses have a primary responsibility to provide quality palliative care to dying patients, their carers and their significant others. We also believe that each nurse's conscientious belief concerning the issue of voluntary euthanasia/assisted suicide ought to be respected and supported, and this obviously can be a difficult situation in a work setting. There is a list of issues that we advocate for on behalf of our members, but I would like to draw attention to two particular points. One is that RCNA advocate for our members on the provision of palliative care and excellent care of the dying to be equitably accessible across all of Australia. We advocate that the role of the nurse be clearly described in relevant social policy and legal acts and statutes and not merely subsumed under the practice of medicine. We advocate that the role of the nurse be prescribed in accordance with the accepted philosophy and ethics of the profession and the codes of practice of the nursing profession. We also advocate that nurses not be given responsibilities that exceed their legal authority to practise.

And the other point that we wish to draw attention to is that we believe it is our responsibility to disseminate information on voluntary euthanasia and assisted suicide to enable the broader nursing profession to always be informed about the varying ethical, legal, cultural and clinical dimensions of this subject.

Prof. McDONALD - I suppose it falls to me to expand on that position, which I fully endorse. I would like to draw your attention to the point where the hammer of the legal, intellectual and theological debate actually strikes the anvil of human misery and human

condition, because that is where nurses live. We actually work at the front end, and we help people to deal with this. Our business is to help people live with dignity and to do that as comfortably as possible and, if there are challenges that cannot be resolved, then to help people to adapt to what lies ahead. That is the business that we are in as nurses, and we do that in every context. My current specialty is in ageing. I am very involved in the human rights movement, and I believe very strongly that people do have a right to make decisions for themselves. Whether those decisions are well-informed or not is not something that I want to get into in this presentation. What I do want to talk about, though, is where nurses are actually involved in this decision.

As regulators, you are considering putting forward a statute that could in the worst possible scenario compel nurses to get involved in something that is completely counter to what we learn to do, what we strive to do, and in doing that you could actually compromise quite a lot of people within the nursing profession by putting them in a situation where they face an ethical, moral and personal dilemma. If I could just diverge for a second, we have a situation where somebody has been given by the courts the right to starve to death in the middle of a nursing home. That is shocking to us, shocking to have people who have learned to care, people who are committed to assisting life, exposed to the spectacle of a self-induced starving to death, which is a horrible way to die. To be in the middle of a situation like that is just appalling. There is no special skill involved in starving to death, so I don't think they should be doing it in the middle of a place where we are set up to assist life and to assist comfort and to promote dignity. That being said, I will get back to what I was supposed to talk about.

As legislators, no doubt you are fully aware of intended consequences, and the intended consequence of this legislation, as far as I can tell, is to provide an option for people who have not found pain relief adequate or satisfactory. On the face of that, that sounds very practical, but as the previous speaker pointed out to you, what safeguards are you as regulators going to put in place for all of the open-gate information and opportunities that flow from this? For instance, as mentioned by the previous speaker also, and I would like to endorse what he said, there are a lot of people who would benefit from somebody having an early death. Inheritance, status, power - all of these things flow in certain circumstances from somebody having a shortened life and somebody else stepping in.

What safeguards do you have in place to make sure that somebody is not selling the idea to somebody who has been neglected, somebody who has been allowed to suffer, the idea that they are perhaps too great a burden on them and that perhaps they should do the right thing and end their life? That kind of thing needs to have safeguards around it because that happens; it happens even now. You have families who try to sell the idea to their elderly relative that perhaps they have become too big a burden financially or emotionally, and it's the human condition that this happens. It is motivated by greed and when you consider this in the light of the level of elder abuse that happens throughout our society in Australia, it's predominantly financial abuse; when you consider that, the motive is there, the motive is widespread. By enacting this legislation you would provide the opportunity for something drastic to happen. You would take that to the next level, and you would be sanctioning it.

The other safeguards you need to think about are things like euthanasia clinics. Is this going to be a euthanasia tourism destination or is it just for Tasmanians? If it is going to

be a clinic, who is going to staff this clinic, because, as I said, it doesn't take any special skill to kill people. These are the sorts of things that you need to think about when you are putting together legislation.

- **Ms FORREST** Just on that point, if I may interrupt, Mr Chairman I have a nursing background so you are among friends here regarding the point that there's no special skill in killing people, it's been said, particularly for people who receive palliative care who have possibly had opioid use for a period of time, that you can't easily kill a person with opioids in those circumstances. So this argument that we hear about the frightfully narrow gap between giving extra medication to relieve suffering that may hasten a person's death, in my mind is not an argument; I think it's different. Intent is one thing there, but also in those circumstances it's not that easy to kill somebody. Can you elaborate on that?
- **Prof. McDONALD** I know of quite a lot of people I move in the world of ageing at the moment who tell me that they have a pill, that when it all gets too much they will just suicide with that, and it concerns me but they have shared that with me. As I say, it's their choice to do that. Palliative care is quite different, and I think some clarification needs to be brought to this whole thing.

Not for resuscitation does not mean not for treatment or to neglect them; euthanasia means that you are killing somebody who perhaps didn't say yes, please. Voluntary euthanasia means that they did say yes, please. Assisted suicide is for somebody who is, for some reason, not willing to go on living and they want some help with it, but in all of these situations the nurse is there, and quite often the nurse is asked to step in in those gaps that you are talking about.

When you've got a palliative care situation where you are trying to promote comfort, relieve pain, maintain dignity, work with the family so that they are prepared for the death, provide all of that for them, yes, it does happen that sometimes you are increasing the pain relief - particularly morphine-based drugs - to such an extent that it does depress the respiratory centres, but that is not the intention of doing that. It does not happen as easily as you might think.

- Ms FORREST That is what I am saying, yes.
- **Prof. McDONALD -** You can actually keep increasing the morphine for people who become resistant to it. There is a point where their body just cannot take any more. It is never predictable and you are never intending to do it but they cross over that point and the respiratory system fails.
- **Ms FORREST** So the difficulty here is knowing whether they stopped breathing because of the morphine or stopped breathing because they were about to die anyway. We do not know that point of death -
- **Prof. McDONALD -** And it is very difficult to actually tell which was the cause of death. I think if you gave one dose of morphine to somebody who was dying and they died then it is probably pretty clear that the morphine was instrumental in that death. But if you have been giving somebody palliation over a period of time and you have had to increase

the dose in order to manage the pain over that time, and you look at the history, there would be no intention there to actually cause the death.

- **Ms FORREST** It is an argument that is often used about the narrowness of the difference. I have heard nurses say that they assisted in the euthanasia of a patient through increasing the midazolam in the infusion. When they had actually sat down with the palliative care specialist and worked out the percentage of midazolam in the infusion, the rate at which it was going - the dilution rate - and how much had to go down the tube before it even got to the patient -
- Prof. McDONALD It could not have been.
- Ms FORREST it could not have killed them. It would not have killed an ant.
- **Prof. McDONALD** A lot of nurses feel that guilt. This is the dilemma that nurses are often thrown into in these situations. Because there is so much media around it, it can get very, very confusing as to where the truth actually lies.
- **Ms FORREST** So you think nurses themselves are confused about what we are talking about at times?
- **Prof. McDONALD -** I do think so.
- **Ms CERESA -** I think the diversity of nursing is so huge that there are times where there are pockets of nurses that perhaps are not as well informed as other areas of expertise are. There is no doubt in my clinical experience that nurses that work in areas such as palliative care, pain management, perhaps in intensive care, coronary-care units where they have that much broader knowledge of pharmacology and certainly areas of aged care compared to nurses that work in other areas, then their knowledge may be greater. Certainly from our perspective as RCNA, we want to make sure that we get the information out to as many people as possible. As we want dignity and dying to be equitable for all Australians, we want the information and the education to be equitable for all nurses as well to have a much greater understanding. Both of you just highlighted that this is always such an emotional issue. It is something that gets people stirred up incredibly, and people can feel really exposed and vulnerable in all settings. It is very, very challenging for nurses. Obviously we are here speaking on behalf of nurses. It can be very challenging for them.
- Prof. McDONALD There was just one other point that I wanted to make about the difference between palliation and euthanasia. I know we discussed them in the one conversation but they are completely different. They really are. The decision to euthanase really needs to be separated out from palliative care. I suggest that once somebody has decided that they want to die rather than live, the argument can be put that it does not really belong in a health system.
- Ms FORREST That is an interesting comment. Do you want to expand on that a little bit?

Ms O'CONNOR - Where does it belong, then?

- **Prof. McDONALD -** I do not know where it belongs. It belongs somewhere else but it does not belong here because it just muddies everything to such an extent that it causes that sort of confusion that we were talking about. It causes people to doubt the integrity of the service; they do not know whether they are going to be at risk of the polls.
- **Mr WHITELEY** I wrote down 'Rossiter' because it has come up a couple of times today. It came up at a dinner party at the weekend. When this issue came up someone said, 'What do you think about this issue of Mr Rossiter?'. I said that is fine. He has made a choice and we have come to that and I have said on the record that that is a choice. But I really struggle. If I had been the CEO of the aged-care facility this is my personal view and I am happy to put it on the record I would have asked him to leave. Why am I uncomfortable? No, but what about the care of my workers, in your case aged-care nurses who, as you very eloquently put earlier, have to be now subjected for whatever period of time that is, which is a bit of a worry. So I am quite intrigued because I think it is a profound observation in that you are saying there does not just have to be a differentiation between terminology; there does nearly have to be a physical dislocation between palliation and those then who make a choice to -
- Prof. McDONALD The purpose is quite different.
- **Mr WHITELEY** And then rather than subject our workers, in your case the nurses, to yes that is very interesting.
- **Prof. McDONALD** If you were to subject workers to that sort of spectacle, what about the WorkCover and the physical distress that comes from that? Does that come from the estate of the person who presented the spectacle that they could not leave? Should the taxpayer pay for that? Should it be Medicare-funded?
- Mr WHITELEY Very good questions.
- **Ms CERASA** Following that line of thinking and the comments that Tracey has made, that then brings in another side of the spectrum of discussion about what defines dignity. If somebody does have the right to make that choice and that choice is made then how do you make sure that a system, whether it be a health system or whatever system, allows them to have that with dignity. That is not what will occur in that situation. An aged-care facility system is designed to do something and it is clearly defined, but this does not fit into that design and that then raises a whole other spectrum of the discussion.
- Mr WHITELEY Is it dignity for those watching?
- Ms CERASA That is right and the dignity for the person.
- **Prof. McDONALD** It is definitely not and it is very stressful. It is completely counter to their whole motivation in life to help people and then they are subjected to this spectacle.
- **Ms FORREST** So you need a whole new category for people to care for people who made these choices?
- Prof. McDONALD We have the health system so perhaps we could have the death system.

Mr GAFFNEY - If somebody starves themselves to death the complications and the pain that they would have to go through to achieve the end could result in quite long suffering. I accept that it is wrong to house them in an aged-care facility but what if there were a clinic for that happen?

Prof. McDONALD - If there was a clinic, yes.

Mr GAFFNEY - If there was a clinic for that to happen and that person is willing to go through that and starve themselves to death because they are in so much pain, and that is the only way they can see out of it, yet we will not allow legislation where we will allow that person to end their life without the suffering, without starving themselves to death. You have doctors and nurses out there who are supportive of this. We have had submissions from nurses saying it should be in and we have had submissions from doctors saying, yes, I am prepared. Therefore if there was a clinic where the person went for their final moments they could do that in a much more dignified manner than starving themselves to death. If you had that choice is that not a compassionate society?

Prof. McDONALD - I can see your point.

- **Mr GAFFNEY** The safeguards are in the legislation and how we manage that. The idea that there is a compassionate society out there that would allow that to happen, is that not -
- **Ms CERASA** I think that is another facet of it. I think that is what Tracey raised earlier around the legal obligations and the safeguarding and monitoring of the public in that setting. That raises a whole different care spectrum. How do you monitor, safeguard and make sure that the legal and moral obligations around it are appropriate and correct?
- Prof McDONALD And that people are not being killed for financial gain.
- **Ms CERASA** Yes. It is just not black and white and that is unfortunate because there are so many aspects of it. You are absolutely right in that we have members who are very passionately for this debate and obviously we have members who are very passionately against this debate. The position statement of the Royal College of Nursing Australia obviously has to respect that diverse view. That is why Tracey and I are here. We are trying to make sure we give a fair representation. It is a very difficult thing because we have nurses who are really only interested in the legal side of it. They are really interested in the legal obligations and you could ask, 'Where is your compassion? What about the caring part of the debate?'. And they say, 'Of course I care. I am a nurse, by nature I care. But what I am really interested in is this, this and this'. So it is quite complex in the different layers or spectrums of it, I guess, in the debate.
- **Ms O'CONNOR** Debra, regarding those nurses who are represented by the Royal College of Nursing who strongly support individual autonomy, the right to choose voluntary euthanasia, why do they support it? Perhaps you could articulate some of those arguments within the profession for voluntary euthanasia.
- **Ms CERASA** We have been here for about an hour and I think that a number of you have made the comment that people would see it from what their perspective of the caring, the compassion, the dignity and the ending of suffering means to them and my experience

with people who feel quite strongly about it is that it is very much motivated by an environment where they see much suffering and no alternative. So for that person to make that choice, it has come to that point where they see no other alternative and therefore, based on that person's right to make that choice, they would argue that very strongly.

Whether there is an alternative or not, it is so hard to make general comments when we are sitting here. Each individual situation that arises is exactly that - it is such an individual situation.

- **Prof. McDONALD** We debate this a lot because in the field of ageing, we talk about death a lot, really.
- Ms O'CONNOR Of course.

Ms FORREST - It comes to us all.

Ms O'CONNOR - It is an occupational hazard, yes.

Laughter.

Prof. McDONALD - Sometimes kindly and sometimes not so kindly.

Ms O'CONNOR - Sure.

Prof. McDONALD - One of the biggest prompts for people to support euthanasia is the awareness of system failure - and I am talking about health system failure. I am talking about medical system failure, pharmacological system failure and nurses trying to relieve pain and promote comfort, and to maintain the dignity of a person, if the system is just not up to it, if the drugs are not there, if the doctors are not available, if the skills are not available, if the beds are not available - it is just so distressing to try to do what you know could be done if you had the resources but then to find that the resources are never going to come, that cost cuts and all the rest of it have reduced hospital beds and health resources to such an extent that you do not have the basic tools to work with in order to achieve the treatment goals that you are looking for.

That is one of the major prompts for nurses, to consider that the suffering is just so awful and we do not have the resources, and no opportunity to get the resources because of government decisions about funding.

- Ms O'CONNOR But can you see why that is a strong argument for a legal framework?
- **Prof. McDONALD** Yes, but I am saying it is a system failure rather than a preference for euthanasia. It is prompting that as an option that is better than living.
- **Ms O'CONNOR** Would you acknowledge, though, that every day in Australian hospitals palliative care wards nurses are part of decisions this is where there is the fine line argument between palliation and voluntary euthanasia when medicines are administered that shorten the life of the sufferer, not that that is the intent, but the knowledge is there that when you administer this medication life will end prematurely?

- **Prof. McDONALD** I am also aware that doctors who write such prescriptions for nurses to follow do not always have nurses who follow them, that nurses will question 'if this is a lethal dose' nurses will question and sometimes doctors do write a lethal dose for nurses to deliver.
- Ms O'CONNOR That is involuntary euthanasia, isn't it?
- **Prof. McDONALD** No, that is fraud because the nurse has not been involved in the discussion, the nurse is put in a position where if you do not check what the dose is, you will have killed somebody with this lethal dose, and what do you have in defence? A Nuremberg defence?
- **Ms O'CONNOR** There is no protection under the law at the moment because there is no law like this in place.
- **Prof. McDONALD** I am saying that nurses are right in that gap and we have to make sure that nurses are not placed in a situation where they are either manipulated into doing something that they are unaware of that results in a death or that they are put in a position where they are forced to compromise their ethical and moral integrity by doing something and have no defence.
- **Ms O'CONNOR** But there is a third way here where nurses, as a compassionate response to the suffering of the patient, are part of a decision to prematurely end a person's life, to relieve suffering, but the consequence is that life is shortened.
- **Prof. MCDONALD** I have never been involved in such discussions and I do not know of anybody who has been involved in discussing the killing of somebody.
- Ms O'CONNOR But you just said before that doctors will write prescriptions for a lethal dose.
- **Prof. MCDONALD** It is rare but it can happen. Part of your registered nursing role is to not give anything that you do not know the potential effect of. You question everything. Just because a doctor writes the prescription, you do not have to give it. If it is a lethal dose, then you report that because that is criminal.
- Ms O'CONNOR But do you think it is being reported all the time?
- Prof. MCDONALD I cannot speculate on that.
- **Ms O'CONNOR** How can you be certain that there is not frequent involuntary euthanasia being carried out in palliative care wards across the country with the intent of relieving suffering?
- **Prof. MCDONALD** I cannot speculate on that. I cannot even endorse that because I am unaware of it. I have been nursing for nearly 40 years and I have never run across that experience. So I do not know who you have been talking to but I have not run across that experience. The only part that I have been mostly involved in is not-for-resuscitation orders and we have a huge discussion around that. A lot of it is

around babies who are congenitally malformed to such an extent that it would awful to maintain them. You just do not resuscitate them, but that does not mean you do not feed them and keep them clean and warm and whatever. You maintain their comfort but you just do not resuscitate them when the end does come. I have been involved in that across the lifespan with burns patients, palliative care patients, elderly patients with advanced Alzheimer's; when the end does come from pneumonia for those people, you do not resuscitate and you do not give antibiotics. That does not mean you do not care for them, keep them clean, warm, fed and hydrated so that they do not die of additional discomfort and pain. But that is about it. I have not experience what you are -

- Ms O'CONNOR Have you worked in a palliative care ward?
- **Prof. MCDONALD** Yes, I have. I have also worked in the palliative care clinical team in the community and, no, that has not come up. I have never, ever been involved in a discussion about killing somebody.
- Ms O'CONNOR No, but just because it is not discussed does not mean that it is quietly not happening in order to relieve the suffering of someone for whom -
- Prof. MCDONALD I would know. I would have guessed.
- **Ms O'CONNOR** So what is the solution, Tracey, for someone who is terminally ill for whom palliative care is not providing relief? What is the solution from the profession's point of view?
- **Prof. MCDONALD** The first thing you would do is find out why it is not working because palliation now really is very good. It really can achieve so much. If you have the resource and access to the drugs, medical expertise and nursing expertise and the environment and everyone is working for this then you can achieve comfort.
- Ms O'CONNOR In every case?
- **Prof. MCDONALD** I have never seen it not work. Very rarely, I have read about cases where it is intractable pain. But I have also seen -
- **Mr WHITELEY** Dr McGushin, who was here from Calvary last week, said that when it gets to that for the very small minority they can be put into an induced coma.
- **Prof. MCDONALD** An induced coma or you can have a minor operation where you just separate the nerve endings and stop the pain going from that particular organ. You can stop the pain but the process of dying runs its normal course. You do not shorten the life. You make that life comfortable. That is the whole goal and there are things you can do for that. You do not have to kill them.
- **CHAIR** Is there a lack of an understanding and education about palliation? Do we not know enough about palliation?
- **Ms CERASA** I would agree with that statement. Whilst I am the CEO of RCNA now, my previous role was as director of clinical services in a large regional hospital. We had a huge cancer care centre and a very substantial, well-established palliative care team but I

would have to say that across the rest of the hospital the understanding would have been poor. I think that is a very accurate statement. It is something that needs to have more education, more exposure, more understanding, more defining, not just within the health professional teams but within the community as well.

- **Prof. MCDONALD** Mixing up of the terminology into one lump is not helping with that confusion because people are now getting the impression that when you say palliation they will think, 'I am not going there; they will kill me'. People out in the community mix all this together because even professionals are mixing it up, so how can the general public be expected to even understand the differences between these they are not even that subtle but there are differences.
- **Mr WHITELEY** In relation to the first dot point on the second page, Debra, which we have had a bit of discussion about today and certainly in the last group of hearings advocacy for provision of palliative care and excellent care of the dying to be equitably accessible across Australia. That links into some of your questions about system failure. So the College of Nursing would have a very strong view that we have a bit of a way to go in relation to the provision of the quality of care that would assist us in this debate.
- **Ms CERASA** Yes. We have recently set up a faculty looking at rural nursing and midwifery in Australia so we are particularly interested because a lot of our member base is in a rural setting and we work closely with our colleagues who have an association for remote area nurses as well. We hear many stories and it is not just in palliative care; it is maternity care and whatever we want to talk about that the further you get from the metropolitan and big centres the less access you have to a broad spectrum of health professionals and trained and qualified nurses.
- **Mr WHITELEY** Ray Groom, the chairman of Southern Cross, probably one of the largest providers of aged-care in this State, said that there needed to be more specialists and GPs developing their skills in palliation and then he said, 'More palliative care nurses are needed'. What is the position of the college in relation to that? There need to be more resources of course, but does there need to be an awareness that we need more palliative care nurses on the ground?
- **Ms CERASA** In our role of working with universities and the undergraduate education of nurses, when we become aware of a particular area we can talk with our college of deans and representatives of nursing education. Continual review of curriculums highlights these types of discussions. If I come back to Mr Finch's comment before about the education, understanding et cetera, I think that is where it is going to come out that it does have to be. It is an interesting debate. The research is quite at odds at the moment about whether we need more in numbers or more in quality.
- Mr WHITELEY In palliative or in nursing full stop?
- Ms CERASA Nurses more broadly. Do we need more palliative care nurses or do we need nurses to have more understanding and a broader diversity or do we need to create more specialty in that area? We need another inquiry into that because that is such a huge debate in its own right. I think it comes back to the essence of what was said here and what Ms O'Connor said before. What I was hearing was around the definitions and the education aspect of it and making sure that nurses because that is what I am interested

in and represent - have a much better understanding through our education. Not just registered nurses in undergraduate bachelor degrees, but also our enrolled nurses. We also have another area of people who are working in delivering nursing care now, which is the unregulated worker or assistant in nursing, whatever name you want to call them. They are working in areas a lot where there may be exposure to this -

Mr WHITELEY - So they could benefit as well?

- **Ms CERASA** Absolutely, and it is a position that we are holding at the moment, how we make sure that education gets to that level of worker as well. There is no point denying their existence, they are here and are making a valuable contribution to health care delivery in Australia in our community so we need to make sure that they are well informed.
- **Mr GAFFNEY** You mentioned earlier about the legal side. Let us put the debate about euthanasia to the side and focus on the bill. If the bill was passed have you had anybody from your organisation legally look at the bill about what clauses would be of greatest concern to you?
- **Ms CERASA** At this point, no, we haven't. We have tried to access our regular legal adviser but we weren't able to get it through in the time frame that we wanted for the responses, but it would be something we could access.
- **Prof McDONALD** Could I ask you something? My understanding of the way the parliamentary system works is that when there is a Commonwealth act that deals with the issue State legislation cannot be enacted on the same matter. Now isn't there a Commonwealth act on euthanasia?
- Ms O'CONNOR The Commonwealth act struck down the Northern Territory legislation.

Prof McDONALD - Yes, exactly right.

Ms FORREST - But that was a Territory, wasn't it? That is not a State.

- **Prof McDONALD** Yes, but that arrangement also exists within the Constitution, so with the enacting of an act at a State level, which is already covered by a Commonwealth statute, surely the Commonwealth has precedence?
- **Ms O'CONNOR** But my understanding is that the Commonwealth act was specific to that Northern Territory bill.

Prof McDONALD - Okay.

Ms O'CONNOR - So if the Tasmanian Parliament introduces a bill such as this -

Prof McDONALD - So they may review that bill?

Ms O'CONNOR - I guess the Commonwealth could come over the top and legislate it out of existence. I am not sure.

- **Mr GAFFNEY** Just on that point then, I think if you did have some paperwork, a legal point of view on the actual bill, that would be very helpful. You have already made a submission and we are asking you for more information regarding specifically the legal side of the bill if it were to pass.
- Ms CERASA We are quite happy to take that on notice and provide you with some feedback.
- **Mr BEST** Just for clarification: are you saying that you believe palliative care should sit separately from health care? Do I have that wrong?
- Prof McDONALD Palliative care is part of health care.
- Mr BEST Right, okay, but your concern is there is confusion about delineation of roles -
- **Prof McDONALD** I do not believe that euthanasia, assisted suicide and voluntary euthanasia sit within palliative care or the health system.
- **Mr BEST** Right, thank you. You might not have used these words and I don't want to put words in your mouth, but are you aware of people who have been requesting euthanasia but have not been able to get it?
- Prof McDONALD People who have what?
- **Mr BEST** Who have begged, who have asked, who have requested and haven't been able to be provided with euthanasia.
- **Prof McDONALD** There was an 18-year-old girl this was fairly recently screaming in pain, sobbing, hitting her head against the wall and in so much pain, begging to be killed, begging to die. She had a broken heart. And that was the most astounding display of pain that I think I have ever witnessed. Her boyfriend had dumped her. And this went on for three days. Now if pain alone is a reason to kill people, then everyone in labour, everyone with a broken heart, is at risk.
- Ms O'CONNOR But you understand this bill deals with the terminally ill?
- **Prof McDONALD** I know. But how do you define 'terminally ill'? If somebody has Alzheimer's disease, it is a disease that will lead to death, and particularly in the end years it will lead to death fairly rapidly. Is that a terminal illness?
- Ms FORREST Those people won't fit under this bill anyway.
- **Prof McDONALD** It opens up all of these things, and you can define different conditions as 'terminal', and that is getting very, very fluffy at the moment. There are a lot of people who are actually saying osteoporosis is a terminal illness. If you have lived beyond 60 or 65 you can have a bit of osteoporosis. It is normal. So you have to be very careful what you are actually putting in a bill, and I think, depending on the agendas of people who want it in or out, you will have to put safeguards around all of this so that vested interests are not served by this legislation.

Ms O'CONNOR - But have you read the bill and seen the safeguards that have been put in?

Prof McDONALD - I haven't read the bill.

- Ms O'CONNOR You haven't read it?
- **Prof McDONALD** No, it wasn't given to me. I was asked to come and talk about our position on voluntary euthanasia and assisted suicide.
- Ms O'CONNOR There are a number of safeguards in the bill.
- **Prof McDONALD** Okay, thank you. And we will, as Debra said, look through this. We will get our legal people to have a look at it and we will get back to you.
- **Ms FORREST** Just on that point, I think Mike asked some questions about the bill itself, and I appreciate that you haven't looked at it, but one of the things that you have identified and which has been raised is the issue of the definition of terminal illness, and also the potential role of nurses I am not sure which clause it is and whether the person should stay with a person until they die. It is on page 10, clause 8(p) top of the page. It starts off with:

'the medical practitioner himself or herself provides the assistance and/or is and remains present whilst assistance is being given and until the death of a sufferer'.

It goes on to talk about other people that may be involved and that is where some of the nurses have raised concerns about their involvement in that. So in the legal advice that you get it would be helpful to look at the potential impact on nurses involved.

- **Prof McDONALD** The danger of medical delegation within this scenario is something of great concern to nurses because it would throw them immediately into a dilemma.
- Ms O'CONNOR But no-one can be compelled to assist under this bill.
- Ms CERESA That was part of the comment that we made that we wanted the nurses' practice to be separate from the -
- **Ms FORREST** That is what I am saying. If that can be clarified because that is one of the issues of concern that has been raised by nurses. A lot of nurses have not put submissions into the committee but I know a lot of nurses and I have talked to them.
- **Ms CERESA -** That is certainly one of the comments that have come back this comment that we had made originally about nurses not being under that umbrella heading of medical practitioners, that it needs to be separate because of the scope of practice and our professional code of practice, as it stands.
- **Ms FORREST** I guess the question is: can your legal opinion determine whether the role of the nurse can be described in legal acts and statutes.
- Ms CERESA Yes, we need to bring that back.

- CHAIR Thanks very much. Is there something you would like to say in conclusion?
- **Ms CERESA -** No, it is quite obvious that this is a subject that is discussed at length amongst the nursing profession. We both attest to the fact that it can be quite emotional when people discuss it. However, we do thank you for the opportunity to come and we are more than happy to provide some feedback and further information. We would be happy to come back if there is anything else we can provide any other time.
- **Ms FORREST** Can I just let you know that the committee has to report by 2 October. I do not know quickly you can get the legal advice?
- Ms CERESA We think this is really important so we will make that move quickly.
- **Prof McDONALD -** I would just like to say that, despite the fact that we have not read this bill, the principles that we have been talking about stand. If they are reflected well in the bill, fine. If they are not, then we will get back to you. But our stand on the principles on these issues, I think, should not be undermined.

CHAIR - Thanks very much.

THE WITNESSES WITHDREW.

Mr NICK MCKIM MP, WAS CALLED AND EXAMINED.

- **CHAIR** Thank you for allowing us to extend overtime with our previous witness, Nick. We will take a verbal submission from you now and then we will ask questions.
- **Mr McKIM** Thank you, Mr Chairman. I start by saying that I am assuming that all members have read the written submission that I supplied to the committee. I do not intend to go through that blow by blow because I would really like to offer the committee as much of an opportunity as possible to ask me any questions in relation to any matters that arisen in members' minds.

I thought I would take the opportunity to, in very short form, make my argument for the reform of current Tasmanian law to provide for voluntary euthanasia and therefore, in my view, providing people with the opportunity to make a choice to die a dignified death instead of an agonising and often humiliating death. Then I would inform you of a couple of matters that have come to my attention since I made my written submission to the committee.

In overview, I would like to make it very clear that my bill seeks to regulate a practice that empirically we know is occurring in palliative care wards right around the country on a regular basis. Again, I make the point that if we regulate a system, there is far less possibility that vulnerable people will be exploited. That is the first point I would like to make.

The second point I would like to make is that current law forces many terminally ill Tasmanians to die an agonising and often humiliating death. I think that is unacceptable and I think the legislators have a responsibility to fix that problem.

I would like to make a final point before I go to the matters that have been raised with me subsequent to my written submission. Current law is archaic and irrelevant to what actually happens in palliative care wards around Tasmania and Australia and certainly around the developed world. Current law is out of step with current practice. I have here - and I seek leave to table it - a study published in the Medical Journal of Australia in 2001 which found that of the doctors who responded to this survey - and I should say these are general surgeons - just over 36 per cent reported, and I quote:

'For the purpose of relieving a patient's suffering they had given drugs in doses that they perceived to be greater than those required to relieve symptoms' -

and this is the important bit -

'with the intention of hastening death'.

I will be very clear about that: so 36 per cent of respondents to this survey have admitted giving drugs with the intention of hastening death. How that could not be manslaughter or murder is beyond me. If this committee hasn't resolved to seek legal advice from the Solicitor-General on whether there is manslaughter or murder motivated out of compassion occurring in palliative care wards around Tasmania, I would suggest it has

abrogated its responsibility. I strongly recommend that you seek that advice from the Solicitor-General as a matter of urgency.

- CHAIR What action have you taken, Mr McKim? Are you bringing this forward now?
- **Mr McKIM** I'm not a lawyer, Mr Chair, but I have looked at the Criminal Code since this was brought to my attention in the last couple of days and it seems clear to me, a layperson, that if a doctor is giving medication with the intention of hastening a patient's death, which 36 per cent of respondents to this survey admitted they have -
- Mr WHITELEY Were they killing them or hastening their death?
- **Mr McKIM** Any time somebody kills anyone all you are doing is hastening their death because we're all going to die sometime. They have admitted giving medication with the intent of hastening death. This is the elephant in the room. I am not a lawyer but I can't see how that isn't at least manslaughter, if not murder. I respect the doctors for doing this but it places them in an intolerable situation, where their desire to act compassionately and in the interests of their patients places them, in my view, in direct contravention to current law and exposes them potentially to charges, and possibly convictions, of manslaughter or murder. That is an intolerably unfair position in which to place doctors and nurses.
- **Mr BEST** But they're not in that position, are they? No-one is being charged, are they, so what's the concern?
- **Mr McKIM** You are right, but this is the elephant in the room and somebody needs to call it for what it is. It is an intolerable situation where a blind eye may be being turned to actions which contradict some of the most serious Criminal Code offences in this State. You are absolutely right, Mr Best, but I would make the point that in the case of Godfrey not only did judge find that current law discriminates against physically disabled people, which it clearly and unarguably does and mounts an argument that the law should be reformed, but also the court ended up acting as a de facto public policymaker in this case because the sentence, which wasn't appealed, was that Mr Godfrey could walk free. You have a situation where, in my view, the massive flaws in current law have turned courts into de facto public policymakers and that is the case because parliaments and parliamentarians have been, quite frankly, too gutless to take the action that should be taken and that is to reform the law to ensure that acts of compassion which is what voluntary euthanasia is; it is motivated only by compassion, not a desire to kill are clearly not illegal.

My bill seeks to regulate a practice that is occurring regularly in hospital wards around the country. Because it is currently unregulated, it is very hard to know how often and in what circumstances it occurs and that is unacceptable. We need to regulate it so that we, as members of parliament, representatives of our communities can be informed fully about what is going on and that would be a consequence of my bill in terms of the reporting provisions.

Mr BEST - Can we have a copy of that?

Mr McKIM - Yes I do seek leave to table it.

CHAIR - Leave granted.

Mr McKIM - Thank you.

The relevant part is about half way down the section on the first page entitled 'Abstract' and it is under 'Results' - 247 respondents and so forth on the very first page.

The second matter that I would like to raise in overview is the accusation that what I am doing is immoral and this has been made directly by many people including the Archbishop of Tasmania. I reject that accusation.

I am motivated by a desire to allow people to exercise control over their own bodies, to allow people who would otherwise die an agonising and humiliating death to make a choice only in relation to themselves to die a less agonising and less humiliating death. My actions are motivated by values of compassion and respect for human dignity and I think they are values overwhelmingly shared by the Tasmanian community - a fact that is reflected in every poll that has ever been conducted in this country or this State showing massive community support for law reform of the type that I am proposing.

By the way, I absolutely welcome the Catholic Church, the Anglican Church and any other religious body participating in this debate and I absolutely encourage it. What I do not support is people who argue that views that are informed by religious beliefs should be forced on people who do not share those religious beliefs. That is what the current law does.

- Mr WHITELEY Can you explain that?
- Mr McKIM Well, I believe -
- **Mr WHITELEY** The two people who gave evidence before you did not come with any religious beliefs.
- **Mr McKIM** I do not even know who they were and I was not here during their presentation so I am not really able to respond to anything that they said.

I was in Oregon recently and I met with a number of people who were involved with the delivery of the dying with dignity framework there. One person whom I met was Barbara Glidewell, who is the hospital ombudsman of the Oregon Health and Science University Hospital in Portland, Oregon - it is the biggest hospital in Oregon. She is the director of the department of patient relations of that hospital and she is or has been involved in clinical patient advocacy, clinical palliative care and clinical pastoral care. She is a practising Catholic, she is an assistant professor in general internal medicine and geriatrics. She is the chair of the Clinical Ethics Consultation Service and she is a senior scholar at the Centre for Ethics in health care.

A couple of days ago after I read the article the Archbishop wrote saying that my bill was immoral, I e-mailed Barbara, whom I met and had a fantastic conversation with while I was in Oregon. I asked her whether she, as a practising Catholic who is actively involved in the dying with dignity framework in Oregon, had any views on that.

Barbara sent me a note with permission to provide it to the committee. I do not intend to read it all out because it is about two-and-a-half pages. I would not presume to take up the committee's time by reading it out aloud when I can table it and you can read it later. I don't intend to speak to most of it because a lot of it goes to her personal experiences, but she hasn't chosen and certainly wasn't instructed by me to do so, to address it to the Archbishop of Tasmania. I would just like to read the last two sentences of it, if I might, and the last two sentences are these:

'Sir, it is with deepest respect and honour that I address you directly. May the soft winds of heaven fill your heart with acceptance of this final act of caring.'

I seek leave to table that, Mr Chairman.

- CHAIR Leave is granted, and we will get copies of that.
- **Mr McKIM** I have presumptively, perhaps pre-emptively made copies of it. I apologise if there's any element of presumption in my making those, but I thought it was unlikely that the committee would deny me leave to table.

The only other couple of things I'd like to say before I obviously welcome any questions from the committee, are these. I have just read the first half of Rodney Symes' book *A Good Death*, and I really do refer it to committee members. You may be aware of Rodney Syme - he has been a doctor for 45 years, he is a urological surgeon and has been an advocate for physician-assisted dying for nearly 20 years. The first three or four chapters of this book are as good an argument for physician-assisted dying or voluntary euthanasia as I have seen and I recommend at least the first three or four chapters of this book to the committee. I will not seek leave to table it because it is my only copy and I am only half way through reading it, so I would just like to refer that to committee members.

The final point I would like to make proactively is in relation to Robert Cordover. I knew Robert for a short period before he died recently. My view is that Robert would be alive today if we had had voluntary euthanasia laws in Tasmania. The reason for that is he wished to spare his family the possibility that they would be placed in a similar situation to the Godfrey case - that is charged with a serious Criminal Code offence because they helped him take his own life.

I do not know how Robert Cordover died, and my understanding is that his death is under police investigation at the moment. I have no idea how that investigation is going, but certainly there have been reports that the matter is being investigated by the police. As I said, I don't know how Robert died, but I have no doubt at all that he would be alive today if the law were different. He is dead today, again in my view, because he sought to protect his family from any criminal charges that may have resulted from any decision they made to help him to end his own life.

This goes back to the current discriminatory law, and Justice Underwood referred to this in his Godfrey verdict, that physically disabled people are discriminated against by current law because they cannot physically end their own lives. Remember, suicide and

attempted suicide are not crimes in Tasmania, so I could kill myself tomorrow and obviously I'd be dead but I wouldn't be charged. I could try to kill myself tomorrow and I wouldn't be charged.

- **Mr WHITELEY** But I can't help you.
- **Mr McKIM** But you can't help me, Brett, and nobody else can. If I am physically disabled to the extent that I can't kill myself, then I am being discriminated against by current Tasmanian law, in my view, and again I think that's a matter that the committee should consider.
- **CHAIR** For the sake of *Hansard*, I wonder if you could elaborate a little on the Cordover situation as to why he found himself in a situation where he wanted to end his life?
- **Mr McKIM** Yes, thank you. I think the best way to do that is perhaps to read a couple of small excerpts from a statement that Robert e-mailed me not long before his death, and I have appended it to my submission. It was his contention that he was being tortured and required to be tortured under current law. I will quote from his statement:

'I have motor neurone disease, a terminally fatal degeneration of nerves and muscle tissue to which the medical profession has surrendered to its paramount entity, death. Nothing can be done to stop the inevitable advance of MND.

The medical community is complicit with the policymakers of torture in not actively working to permit the resolution of our suffering by our voluntary death, and they continue to support our torture by washing their collective hands of us, to let us suffer through the full disease cycle.

The first torture is the indeterminate death sentence. I do not know how long I am to be held in this Guantanamo, and cannot be told. What I do know is that all my voluntary muscles will continue to degrade until I cannot walk, talk, use my arms or hands, swallow and, finally, unable to breathe, I will expire.

The sentence is a humiliation of any measure of my humanity. The indeterminacy of the sentence is amongst the worst type of existential suffering.

The infamous torture of this decade at Guantanamo Bay is 'water-boarding'. At least once a day, I am water-boarded, choked by a drink of water or often on my own drool, so I cannot breathe and I believe I am about to die.'

He goes on to say:

'Another torture being perfected by the American government agencies in charge of these things is the 'stress position'. Lying down is my stress position. If I lie prone or supine I cannot breathe, so I am forced to lie on my side. Since my muscles are degenerating, I quickly get pain in my shoulders and hips, forcing me to roll onto the opposite side every

10 minutes. This leads to the next of the admitted methods of torture, sleep deprivation. Rolling around in pain keeps me awake most of the night.'

I will just read a final point, if I might. Again, these are Robert Cordover's words:

'The prognosis for me is worse suffering and death. Relief and true palliative care should start with the reassurance that physician-assisted death will be available when I need it. I do not want to die today, but I do know that there will be a time when the continuation of these tortures will result in the rational decision to end my life before deteriorating to a fully paralysed state, totally incapable of communicating, dressing, washing, toileting or eating. I want to end my suffering with a bit of dignity remaining and to retain some autonomy over my life by having sufficient control to end it when I am ready.'

He has described his circumstance there and I defy any member of the committee or anyone else to say they would not be considering ending their own life in similar circumstances.

It may well be - and fair enough - that some people would not make that choice, and I respect people in that position deciding to suffer through until nature ends their life or an incapacity to breathe ends their life. That is people's choice. But what we currently do, through our archaic, irrelevant laws, is force people to take that choice, to die an agonising and humiliating death, and prevent them from choosing for themselves a death that is relatively quick, relatively painless and relatively dignified. That is the nub of this debate.

Just to respond directly to your question, Mr Chair, can I say that I have met Robert Cordover a number of times. I want to reject media criticism that has been made of me that I drafted my bill to respond solely to the Cordover situation. That is untrue. I had never met Robert Cordover until after my bill had been tabled, so those Labor candidates in Denison who seek publicity for themselves by making that accusation are wrong.

However, my view is that Robert Cordover saw and understood what was lying ahead for him. He did not want to place his family in the same situation that resulted in the Godfrey case, and a finding of guilty in that case. He therefore, I believe, made the decision - a sensible decision, in my view; the same decision that I would have made in his circumstance - to end his life earlier than he otherwise would have done if there had been capacity in the law for him to be assisted to die a dignified death.

I am happy to take any questions the committee has.

- **Ms O'CONNOR** Mr McKim, there has been a lot of discussion about improvements in palliative care and we have had the nurses here today saying that basically when a nurse is part of decision to administer medication that effectively shortens life, that is simply good palliative care. What do you think is the difference between that and voluntary euthanasia?
- Mr McKIM There are a number of things I would like to say in response to that. Firstly, a lot of people have said, and the AMA believes, that we should not be discussing

euthanasia or voluntary euthanasia until palliative care is as good as it can be. In my view that is an argument for never discussing voluntary euthanasia because palliative care will continually improve, and I hope it does. I also make the point that, in Oregon, it has clearly and empirically been shown that introducing a dying with dignity framework has led to massive increases in funding for palliative care, massive increases in public debate around how to improve palliative care and much better palliative care outcomes. That is empirically shown in the Oregon data. So what I am saying to those who say we should not be debating VE until palliative care is perfect, is that if you want palliative care to be as good as it can be, let us introduce voluntary euthanasia.

- Ms FORREST Could you table that evidence?
- Mr McKIM Yes; I am not sure if it has been tabled already but I can. It is referenced in my submission. I have two studies from Oregon that are both referenced in my submission but I am happy to table them. This is the most recent one, from summer 2009: 'The Ten Year Experience of Oregon's Death With Dignity Act'. I apologise, I was not aware that I would be asked to table it but I would be happy to provide the other one to the committee in the future, which is a study from a couple of years ago from Oregon as well.
- **CHAIR** Just on that point, are you able to make a comparison between the palliative care circumstance in Oregon and our palliative care situation in Tasmania and Australia?
- **Mr McKIM** Unfortunately I am not, Mr Chair. I did not go to Oregon to examine their palliative care system, I went to examine and interact with people who worked in the framework of dying with dignity in Oregon so I have done no work on comparing Oregon's palliative care system with that of Tasmania.
- CHAIR Thanks very much.
- Ms FORREST Nick, you say that one of the purposes of this bill is to remove the discriminatory aspects of this. Claims have been made that this bill actually discriminates in a different way; it discriminates against people who do not have the mental capacity to -
- Mr McKIM The mental capacity?
- **Ms FORREST** They are not competent to make a decision like that for example people with dementia or people suffering extreme psychiatric disorders. That is the first point I would like you to address your mind to. The second point is that I know there are maybe pockets of doctors saying that they are keen for this and I say without equivocation that all doctors I have spoken to support the principles around the withdrawal of treatment, not instigating treatment that is futile, and increasing medication to relieve suffering, but they have all said they do not want to be giving a drug with the intention of killing somebody. The colleges also say that. The July 2009 Medical Council code of practice makes no firm position on it either way, but it does not suggest that we should be heading down that path. The AMA have a very strong opinion against it. So it would appear that this is a bill that will basically exempt medical practitioners from the Criminal Code should they participate in that, which is something that, from my research, is not something they are seeking or want.

- Mr McKIM Okay. Firstly, my bill is very strongly safeguarded. There is a requirement that a psychiatric assessment be conducted and that a registered psychiatrist form a view that the sufferer is mentally competent, so that is how I would respond to the first point that you made, Ms Forrest. In relation to the second point, I do not have the exact numbers in front of me but there was a survey done in Victoria a number of years ago that showed more than half the doctors surveyed actually supported voluntary euthanasia. If the AMA is strongly opposed to VE - and that is the first I am aware of that because that is not what their written policy on their web site says - then in my view they are not accurately reflecting the views of many of their members. My bill makes it abundantly clear that no person or organisation can be compelled to participate in the dying with dignity framework. That applies to individual doctors, health care providers, including Catholic health care providers. Again the Archbishop is wrong when he raises concerns that it will place Catholic health care providers in an intolerable position. If he read my bill he would have understood my bill makes it clear that no person or organisation can be compelled to participate. In other words, there is an out for any doctor or organisation that has a moral or ethical view that they should not participate in the framework. That was deliberately written to try to defuse the kind of attack that it has had to put up with anyway.
- **Mr WHITELEY** Hypothetically in the case of a Catholic hospital, which you say would be quite free, if they have somebody in a palliative care situation in their care, say, in Launceston, if that person seeks assistance, under your bill you say there would be no ramifications for the hospital to say no. Whose responsibility then would it be to find somewhere else for that patient to be cared for?
- **Mr McKIM** That is not explicit in the legislative framework and, I think, appropriately so. I can refer you to the Oregon circumstance where again it is open to either individual doctors or health care providers not to participate in the dying with dignity framework. What happens there is that there are doctors and health care providers who, it is widely known, are prepared under the safeguarded laws in Oregon to participate and the patients or sufferers are referred to those doctors and to those health care providers for assessment as to whether it would be appropriate that they be assisted.
- **Mr WHITELEY** So it is possible that they could in a sense be told, 'We can't help you in this hospital', so basically they would discharge themselves and find some other place of care?
- **Mr McKIM** Not necessarily be discharged, but this is just a reflection of something that occurs every day in Tasmania now. If you are not happy with the service you are getting from your doctor you go to another doctor.
- Ms FORREST If you can get into one.
- **Mr WHITELEY** No, I am talking about if you are in a palliative care situation in a ward in a hospital.
- **Mr McKIM** Okay, thanks. I will just respond to Ms Forrest's interjection, and I will come straight back to you, Brett. She said, 'If you can get into one'. That's fine, but that is a resourcing argument, not a legislative framework argument.

So what I am saying to you, Mr Whiteley, is that presumably the organisation which indicated that it did not wish to assist someone to die a more dignified and less agonising death would still continue palliative care treatment, if that is what was ongoing. I am assuming they would not vindictively choose to withdraw that treatment.

- **Mr WHITELEY** Of course. But what if the patient is saying, 'No, I want to participate in VE'?
- **Mr McKIM** Then that patient or his or her representatives would, as they normally would for many other issues currently, seek medical assistance elsewhere.
- Mr WHITELEY Do they discharge themselves and find somewhere -
- **Mr McKIM** No, I wouldn't think they would discharge themselves. As I said, I think they would do their best to urgently find a doctor or health care provider who would help.
- **Mr WHITELEY** But no-one with the willing intention to be involved. For a doctor who would agree with VE, you wouldn't expect for one moment that Calvary Hospital, for example, would permit that doctor and their associates to walk into that hospital to undertake whatever it is that they intend to do.
- **Mr McKIM** Sure. That is a matter for Calvary Hospital, and I understand that was a hypothetical example, but that is a matter for the health care provider.
- **Mr WHITELEY** How would you respond, though, as someone who has strong views in relation to discrimination in other matters? What would your view of that be, that they should have the right to walk into that person's ward in Calvary Hospital?
- Mr McKIM I have not addressed my mind to that.
- **Mr WHITELEY** But it is a big issue, certainly for that group it is, or for the aged care facilities represented by Southern Cross here this morning. Carolyn gave evidence about what would happen if they were not participating. Will people come under the cover of darkness, so to speak, as doctors and visitors at 8 o'clock tonight and attend to this patient in the care of an aged care facility that does not put its imprimatur on VE?
- Mr McKIM That would be trespass, in my understanding of the law. I am not a lawyer.
- Mr WHITELEY It would only be trespassing if they were told not to come in, but anyway.
- Ms FORREST They could come as visitors, you are suggesting, aren't you?
- Mr WHITELEY That was the evidence that was just put before us.
- **Mr McKIM** I don't think it would be any different to the current circumstances, which is that if someone is unhappy or dissatisfied in any way with the medical service they are being provided with, they retain the right to seek a health care provider or doctor who has the capacity to satisfy them. That is what exists right now and it would continue to be the same.

Mr WHITELEY - In tabling the evidence in relation to the survey, is your evidence today that you wouldn't feel there is much variation in Tasmania - though that was an Australia-wide thing, I presume?

Mr McKIM - Yes.

- **Mr WHITELEY** So is it your evidence today that you would suggest that 36 per cent of surgeons are intentionally killing their patients in Tasmania?
- **Mr McKIM** That is the empirical data from this survey on a national level and I know of no reason why that wouldn't be similarly reflected in any data sought in Tasmania, but there is no data that is State-specific.
- **Mr WHITELEY** That is why I cushioned my question with the fact that, whilst it is an Australia-wide survey, you have tabled it as support to your argument.
- Mr McKIM Yes.
- **Mr WHITELEY** So by inference your evidence today, that you want us to take on board, is that one in three surgeons are involved in intentional acts to kill people?
- **Mr McKIM** In Australia one in three respondents to this survey have admitted that they are involved in administering drugs with an intention of hastening death. In my view, I can't see that is not either manslaughter or murder and I urge you to seek legal advice from the Solicitor-General in this matter.
- **Ms FORREST** I haven't had a chance to read that document, but there are questions about the methodology that is being used and the rigour of the process. Surgeons, generally, provide surgical procedures - and we are talking about the College of Surgeons. These are people who have been accepted into the College of Surgeons - not GPs, physicians, psychiatrists or palliative care specialists; they are surgeons.
- Mr McKIM They may be all of those things as well; I just don't know.
- **Ms FORREST** Well, that's the thing. Those people who would be in a position where they would be likely to be giving drugs to someone who would need to have that level of treatment to relieve their suffering, I find staggering. Intellectually I find it staggering.
- Mr McKIM I'm just giving you the empirical data, Ms Forrest.
- Mr WHITELEY Empirical, though, means that it's trustworthy.
- **Mr McKIM** It is the data that has been gathered with an open methodology, which is available for anyone who wishes to examine it.
- Mr WHITELEY That's right, but you're choosing to use it in support of your bill today.
- **Mr McKIM** What I am suggesting is that this data raises serious questions about legality of what is going on in palliative care wards around the country. Again, I make it very clear

that this is motivated, in my view, by compassion. What these doctors have admitted doing is motivated by compassion. The point I am making is not having a crack at all these doctors; I am having a crack at the law, and rightly so. The law is archaic. It leaves doctors in an intolerable position; it leaves sufferers of terminal illnesses in an intolerable position and anyone who is arguing against reform of the law is arguing for that to continue. Quite frankly, I think that would be disgraceful.

- CHAIR Did you say you've only just come across this information?
- **Mr McKIM** It is referenced in Dr Syme's book, which I read yesterday, and I had my office look up this study for me this morning.
- CHAIR This is from 10 years ago?

Mr McKIM - From 2001.

- **Mr WHITELEY** I am just curious as to your linking this with surgeons, but in the very next breath you're talking about it happening in palliative care wards. I have visited palliative care wards often, I don't see too many surgeons in palliative care wards.
- Mr McKIM I'm not sure about that.
- **Mr WHITELEY** You might see the occasional one but they're not running around like rabbits.
- **Mr McKIM** I think you'd find that surgeons regularly visit palliative care wards. Dr Syme himself is a surgeon. If you read under the 'results' section, it is reported 'for the purpose of relieving a patient's suffering'.
- Mr WHITELEY It doesn't talk anywhere about palliative care wards?
- **Mr McKIM** No, it doesn't but we know that medication is given and the AMA supports this happening in palliative care wards in the knowledge that it may hasten death.
- Mr WHITELEY That's right we've had evidence given about that, even by Calvary nurses.
- **Mr McKIM** The point I make, and I am happy for anyone to respond to this, is how could that not be manslaughter?
- Mr BEST Well, why is it manslaughter?
- Ms FORREST The intent.
- Mr McKIM No, you do not need intent for manslaughter.
- Mr BEST How do you know it is manslaughter?
- Mr McKIM You do not need intent for manslaughter, as most of us know.

Mr BEST - How do you know it is manslaughter, then?

Mr WHITELEY - I don't think it's our responsibility to respond.

Mr BEST - No, how do you know it is, because you're making the allegation?

- Mr McKIM Let's be clear I am not making the allegation -
- Mr BEST Yes, you did.
- Mr McKIM No, what I said -
- **Mr BEST** You just asked me to answer the question and I am saying to you how do you know?
- Mr McKIM What I am saying is how could it not be? That's the question.
- Mr BEST Why is it?
- **Mr McKIM** I haven't said that it is. I am not a lawyer. What I have said is how could it not be, and I have not had any rational response from any committee member.
- Mr BEST Well, it isn't.
- CHAIR You have suggested we take advice from the Solicitor-General?
- Mr McKIM My word I do.
- CHAIR Ms Forrest, have you had your previous question answered?
- **Ms FORREST -** No, I think Nick misunderstood what I was asking in the first bit of my question. I asked about discrimination. There are people with a view and I tend to have a similar view that this bill, in itself, discriminates against people who are unable to fit in under the bill.
- Mr McKIM I see; in other words it's too heavily safeguarded?
- Ms FORREST Potentially, yes; it would stop people who are suffering from severe mental illness, people who are suffering -
- Mr McKIM Okay, thank you.
- Ms FORREST from a whole range of other things who are not competent -
- Mr McKIM Thank you; I did misunderstand that question and I apologise for that.

If people would like to make that argument, that is certainly a matter for them. Can I say a couple of things, though, in response? Firstly, if the committee or the House form a view, or any member forms a view, that the bill ought to be amended to make it better to remove any drafting issues or to remove any discrimination inherent in it, I absolutely

would be prepared to consider any of those amendments in good faith. Nobody is perfect here, and if this bill can be improved and if some of those matters can be taken care of through amendments, I would be prepared to consider them as, I presume, would every other member of the House, because this bill will be debated this year on the Floor of the House. I guarantee it.

- **Ms FORREST** I want to go through some of the points Nick raised in his submission relating to the bill but maybe other people have questions first?
- **Mr BEST -** I am interested in relation to palliative care and your findings of the palliative care wards in Tasmania and how you think they're not catering for these people what you found when you went in there?
- **Mr McKIM** Sorry, what do you mean my findings that they're not catering for these people?
- Mr BEST I think you said there is manslaughter and murder around palliative care.
- Mr McKIM No. Can I be clear about what I have suggested?
- Mr BEST Yes.
- **Mr McKIM** I do not see how what is going on what I believe is going on from empirical data in palliative care wards and other places in hospitals cannot be manslaughter or murder, and I think we have a serious problem -
- **Mr BEST** That's not the question, though.
- **Mr McKIM** on our hands and I'm naming the elephant in the room here today, that's what I'm doing.
- **Mr BEST** Sure, you can that's not the question I'm asking.

When you were speaking to people in the palliative care wards in Tasmania -

- Mr McKIM Do you mean terminally ill people?
- Mr BEST Yes, and families when you visited the palliative care wards that you said you were visiting -
- **Mr McKIM** See, Mr Best, the problem is that you keep putting words in my mouth and if you can just refer me to the statements it would make it much easier for me to answer.
- **Mr BEST** Okay. At the start of your contribution you said that people are forced to die agonising and undignified deaths in palliative care wards in Tasmania and around Australia, so I am asking you about your particular visits to the palliative care wards.
- **Mr McKIM** I've never said that I visited palliative care wards but what I can tell the committee is I have visited palliative care wards but I'm not going to talk about the details of that because it was a personal circumstance.

- **Mr BEST** Sure. So in relation to your bill and this inquiry, you've not visited a palliative care ward in Tasmania?
- **Mr McKIM** My bill is informed by my personal views and those personal views have been influenced by many things that have happened in my life, including visits to palliative care wards, which I'm not going to go into detail about.
- **Mr BEST** I understand and respect that; I'm not asking you to go into that because that is not what my question is about. What I am saying is that you have brought a bill into parliament, you have argued quite strongly about and I will just quote back to you what you've said about forced agonising, undignified deaths in palliative care wards in Tasmania and around Australia. I am asking in relation to the bill that you've tabled and the arguments you have put forward, what investigations have you done in and around palliative care wards in Tasmania and Australia? When have you been to the palliative wards and spoken -
- Mr McKIM I am relying on empirical data and speaking to health professionals -
- Mr BEST So the answer to that one is no, is that right?
- Mr McKIM What is the actual question?
- Mr BEST Have you visited palliative wards in Tasmania or around -
- Mr McKIM I've just told you I have, but I'm not prepared to talk about that -
- Mr BEST No, but in relation to the bill.
- Mr McKIM As I said, this bill is informed by many things that I believe and hold dear to myself, and part -
- Mr BEST I understand that, but could you answer the question?
- Mr McKIM I am trying to.
- Mr BEST Is it yes or no? Have you visited palliative care wards in relation to the bill just recently have you -
- Mr McKIM Please define what you mean by 'in relation to the bill'.
- **Mr BEST** Okay. You have drafted a bill for legislation that you want us in Parliament parliamentarians, that is to pass.
- Mr McKIM Yes.
- **Mr BEST** When I asked the question, you were saying to me that you had a personal circumstance some time ago and you don't want to discuss that. I am not asking about your personal circumstance, I'm asking what recent investigations have you undertaken

personally in regard to palliative care in Tasmania or around Australia regarding your bill?

- **Mr McKIM** Many, by speaking to professionals who work in the palliative care sector; by speaking to terminally-ill people who have undergone palliative care; and by speaking to the families of those people.
- Mr BEST So have you visited any palliative care wards? That's what I want to know.
- Mr McKIM Hang on yes.
- Mr BEST You have just recently?
- **Mr McKIM** I have visited a palliative care ward in circumstances that I'm not prepared to talk about in front of this committee.
- Mr BEST Right. I think the answer to that one could be no, then. In relation to -
- Mr McKIM Hang on. The answer to what one?
- **Mr BEST** You keep talking about your personal situation and I'm not asking about that. I am asking about the legislation that you're putting forward and I think you're trying to avoid answering the question, which is that you haven't actually been into any palliative care wards so you don't really know what you're talking about.
- **Mr McKIM** Hang on, excuse me; I have definitively told the committee I have been into a palliative care ward.
- **Mr BEST** How long ago?
- Mr McKIM I am not prepared to talk about the circumstances.
- Mr BEST Just give us a clue, was it five years ago?
- CHAIR I think you're splitting hairs here.
- **Mr BEST** No, but this is the case the member's putting forward, and I think if he wants to run his argument then we've got a right to know the substance behind his argument.
- **CHAIR** I think he's presented as much of an answer as he is prepared to submit at this stage.
- **Mr McKIM** I only got halfway through it before I was rudely interrupted, but, anyway.
- Mr BEST You don't answer the question -
- CHAIR Is there another question, Mr Best?
- **Mr BEST** You talked about Mr Robert Cordover who, sadly, is no longer with us. I am wondering what palliative care counselling he had in relation -

Mr McKIM - I don't know.

- Mr BEST I don't have any more questions, based on that answer.
- **Mrs BUTLER** Representatives of the Royal College of Nursing were talking about the difference between euthanasia and health, and there was a suggestion that perhaps we should set up euthanasia clinics as a completely separate entity. I wonder if you'd like to speak to -
- Mr WHITELEY It wasn't suggested by them. Mr Gaffney suggested it.
- Mrs BUTLER I think Ms McDonald suggested it.
- Mr WHITELEY She didn't actually suggest it but, anyway, check the Hansard.
- Mrs BUTLER She suggested it be separate.
- **Mr WHITELEY** They're separate issues, but I don't think she actually endorsed the idea of necessarily setting up clinics.
- Mrs BUTLER Somehow to be managed outside the health care setting.
- **CHAIR** Her comment was that there is no place for euthanasia in a health care setting that was the point she was making.
- **Mr McKIM** Okay. The first point I would make is my bill deals only with voluntary euthanasia, which is a subset of euthanasia. So let us be clear: I am not proposing involuntary euthanasia such as does exist, for example, in Holland, where a bioethics committee examines cases and makes recommendations in relation to involuntary euthanasia in cases of, for example, babies that are born without the capacity to sustain life without artificial assistance.
- **Mr WHITELEY** What's your understanding of where the legislation commenced its journey in the Netherlands?
- **Mr McKIM** I don't know, but the reason I know that there is a system of involuntary euthanasia in the Netherlands is that opponents of voluntary euthanasia also often deliberately, in my view seek to confuse the debate by saying, 'This is the start of a slippery slope', and the problem with voluntary euthanasia is that, in Holland, they have a voluntary euthanasia system but there are also *x*-number of deaths per year of involuntary euthanasia. The point I make is that Holland has a legislated involuntary euthanasia system which my bill does not seek or propose.
- Mr WHITELEY It started as voluntary.
- Mr McKIM No, I do not know that it did.
- Mr WHITELEY Yes it did, from the submissions that we received.

Mrs BUTLER - Mr Whiteley, you are going off on a completely different track.

Mr WHITELEY - Sorry.

- Mrs BUTLER Can we get back to my question, please?
- Mr WHITELEY I was responding to what he said.
- Mr McKIM Do not worry, Heather. I am used to that happening every day in the House of Assembly.
- Mrs BUTLER Yes, I am used to pulling it back too.
- **Mr McKIM** Could you clarify the question, because there was a bit debate about what was actually said? So if you would just like to put the question to me again I will try to answer.
- **Mrs BUTLER** Given that the population is ageing I would assume that this is an issue that is going to continue into the future I wondered whether you have put your mind to the question of whether euthanasia stays within the health system or whether you think that there might be a separate entity or a separate direction in which it needs to go?
- **Mr McKIM** My bill does not propose either of those. What it seeks to do is provide a legislative framework in order for people to make a choice to die a less undignified and less agonising death. In Oregon, the death with dignity framework is practised within existing health structures. So it is practised at the Oregon Health and Science University Hospital, for example. I also visited a doctor who runs a community health clinic in Portland, Oregon who issues prescriptions under the death with dignity framework, Dr Nick Gideonse. Often people for whom he prescribes choose to die at home. Can I say that there is a prohibition against people choosing to die in a public place in Oregon. In other words, they can choose to die in a hospital, in the buildings of a health care provider or in a doctor's surgery or at home. They cannot choose to die in the local park.
- Ms FORREST Under that legislation?
- Mr McKIM Yes.
- **Ms FORREST** As opposed to a suicide or running your car in front of a truck, for example. You are not talking about that sort of suicide?
- **Mr McKIM** No, I am talking about deaths within the legislated death with dignity framework. I do not want to talk about driving cars under trucks. I do not think it is helpful.
- **Mr GAFFNEY** Nick, you mentioned that you would be quite amenable if somebody wanted to put forward some amendments to the bill because that is the process?
- Mr McKIM Yes, absolutely.

- **Mr GAFFNEY -** You may not wish to answer this, but since the bill has been introduced and you have had further discussions and further readings, is there anything about which you would now say, 'I think I might have missed something?' For example, the requirement to be a Tasmanian resident for 12 months. Is there anything there that you would seek to change to make it a better bill?
- Mr McKIM I have not formed a view at the moment that the bill is deficient, but I am certainly open to listen to people's arguments in relation to any aspects that they think could be improved or are deficient and need fixing. Specifically in relation to the residency clause. There is a similar residency clause in the Relationships Act in Tasmania. I made a decision to include that in my bill because I knew that opponents of voluntary euthanasia would run the death-tourism angle. As with the Archbishop, unfortunately my inclusion of those provisions has not stopped opponents from running the death-tourism angle as part of a fear-and-smear campaign against my bill. I think that it is appropriate because ultimately we are Tasmanian legislators legislating for Tasmanians. I believe that in that context the residency requirement is appropriate. It has been raised with me by one or two people that it may be unconstitutional. My response to that is that lots of things might be unconstitutional. Ultimately you do not know until you get to the High Court because lawyers often have different opinions on matters. I have no reason to believe that that is unconstitutional. Some people believe that it is, and I have heard opponents of voluntary euthanasia raise that issue. My view is that it is not, but I am not a lawyer and ultimately only the High Court would make that determination. However, I make the point that a similar provision has been in the Relationships Act for a number of years now and it has never been challenged.
- **Mr GAFFNEY** I had an interesting conversation with a friend of mine who is a doctor from the mainland and he said that one difficulty was that, if the legislation is passed, you are going increase the health burden on a small State for those people who will need care over the 12-month period that they have to be here. That was an interesting observation.
- **Mr McKIM** Oregon has a less onerous residency requirement. From memory, I think it is 30 days, but I would not like to be hung, drawn and quartered if I'm wrong about that because I haven't checked it recently. There is very little evidence of anyone moving to Oregon, even for 30 days, to get access to their framework. Only 341 people have accessed the framework in Oregon in well over the decade that it has been in place, and that is in a State with a population many times that of Tasmania.
- **Mr WHITELEY** I do not think the bill extends to a residential component for the medical practitioner.
- Mr McKIM That is correct.
- **Mr WHITELEY** So it is conceivable that Dr Nitschke could start up an active practice as a VE advocate in Tasmania?
- Mr McKIM Do you mean as a provider?

Mr WHITELEY - Yes.

Mr McKIM - My understanding is that he already does, doesn't he?

- Mr WHITELEY Not within a legal framework.
- Mr McKIM Exactly. I rest my case.
- **Mr WHITELEY** You don't have to rest your case. That is not my point. My point is there is no component of residency for a -
- **Mr McKIM** That is correct. I don't know what Dr Nitschke does, and I have nothing to do with him - I have never met him or spoken to him - but he is operating in a completely unregulated framework at the moment. What my bill seeks to do is regulate a practice that is already occurring and, by doing so, reduce the risk of vulnerable people being exploited, increase the capacity of parliaments to understand what is going on, and ensure that there is parliamentary and medical oversight of this practice.
- **Mr WHITELEY** Nick, you would understand absolutely that if you had stated that he is involved in such activity, you have a responsibility to report it, if you know of it or any details of it.
- Mr McKIM I actually do not know what he is doing.
- **Mr WHITELEY** No, I am giving you an opportunity to clarify what you meant and what you said. Because it is an illegal activity and if any of us were to be aware -
- Mr McKIM Sorry, what is an illegal activity?
- **Mr WHITELEY** I mentioned that someone like Dr Nitschke could come to Tasmania and you said, 'As he already does'.
- Mr McKIM He was in Tasmania recently.
- Mr WHITELEY You then said, 'I rest my case'.
- **Mr McKIM** The point I'm making is that whatever Dr Nitschke does and whatever Dr Syme does and they are very different in the way they approach this matter, as I understand it is done in a completely unregulated environment.
- **Mr WHITELEY** True, I don't disagree with that, but in this process, when we make statements such as 'we know it happens' or 'I know of a case', make no mistake, under law we have a responsibility to declare that knowledge.
- **Mr McKIM** We are privileged right now. I have no idea what Dr Nitschke does. I've read media reports about what he does and I am quite dubious about them because he is operating in an unregulated framework.
- CHAIR You did make that point.

- **Mr WHITELEY** I am just saying we don't want to give an impression that people can have knowledge of surgeons walking into palliative care wards, intentionally killing people and then not taking the responsibility on board, in a legal sense, to report such cases.
- **Mr McKIM** I am relying on the data in this survey and I have been very clear today that I do not see how that cannot be manslaughter or murder. I do not know why it is not being investigated by police and I urge you to seek urgent legal advice from the Solicitor-General. I think we have got on our hands right here the same kind of issue that saw the Parliament recalled to deal with the abortion issue a number of years ago and it was urgently recalled.
- **Mr WHITELEY** But give us an example of where is should be reported to be investigated? That is my point. You cannot make those comments. If there is a case, where is somebody to report it?
- Mr McKIM I refer you to the first three chapters of Dr Syme's book where he clearly admits conducting interventions -
- Mr WHITELEY But he is not in Tasmania.
- Mr McKIM He was in Tasmania recently.
- Mr WHITELEY He is not practising in Tasmania.
- Mr McKIM My understanding is that Robert Cordover's death is being investigated by Tasmania Police.
- **Ms FORREST** If he was acting as a medical practitioner outside the jurisdiction where he is registered, that could be the issue there.
- **Mr McKIM** I do not know what they are investigating. I will just refer to you to first three chapters of his book where he admits, and he admits he leaves himself open to charges, and nobody has charged him. I wonder why that is.

I have been accused of being a sensationalist by Mrs Butler -

- Mrs BUTLER You do not have Tasmanian evidence direct, from what I have understood.
- CHAIR Let us not joust. We do not have much longer.
- **Ms FORREST** There have been a number of issues raised in relation to the bill. I have had advice from a number lawyers that it is a really poorly drafted bill. There are a number of problems with it, Nick, and some people feel it cannot be amended to deal with these problems and other people feel maybe it could be. Whose job is to try to amend it? Do you suggest the committee should look at those amendments and make recommendations about amendments? Let us start off with the definition of terminal illness, that is raised as an issue that is not clear. It does not really make it clear as to what we are intending here.
- Mr McKIM Do you want me to address these as you go through them?

- **CHAIR** I am wondering whether we might address your queries when we have the Law Society in. The points can be made there and then that would be available for Mr McKim to read and for you to make your points about the legislation.
- **Mr McKIM** I think the committee should seek the advice that it thinks it needs. It should make recommendations about matters that it is concerned about. If the committee forms a view that there is a deficiency in any definition or any other aspect of this bill, the committee should make recommendations in relation to that. Then, as is the normal course of events, the House and, if it gets to the Council, the Council would consider those during the debate.
- **Mr BEST** In relation to your mentioning again the suspicious circumstances or the investigation of Mr Cordover's unfortunate death, being in Parliament I was aware of his attendance there, and no doubt you spent some time with him discussing the proposed legislation or things of that nature. Obviously you must have discussed with him this matter at certain times. I am just wondering then why you didn't talk to him about palliative care or mention palliative care counselling?
- **Mr McKIM** Well, he could not talk. He could never talk while I met him, so my communications with him were verbal from my end and written from his end. The reason that I did not talk to him about palliative care is that we spent our time discussing voluntary euthanasia.
- **Mr BEST** Given that you are saying it is now being investigated, you did not feel a duty of care to raise what options might have been available?
- **Mr McKIM** The fact that his death is being investigated is something I was not aware of at the time he was still alive.
- Mr BEST I realise that, but now you don't think that maybe you should have just -
- Mr McKIM You are asking me if after his death -
- **Mr BEST** He came to you as a constituent, as constituents come to us all the time. You did not think then to pass on information about palliative care?
- **Mr McKIM** To pass on information about palliative care to Mr Cordover? I was not Mr Cordova's doctor, and I am not a palliative care expert. It would have been well -
- Mr BEST No, but you put yourself up in Parliament as being the eminent spokesperson on euthanasia, so I would have thought -
- **Mr McKIM** Chair, this member has asked me a number of questions that he has refused to let me answer in full. I just want it on the record.
- Mr BEST Rubbish!
- Mr McKIM The Hansard record will show that quite clearly.

- CHAIR Okay, thanks, Mr Best. I will give you the opportunity now, Mr McKim, to sum up.
- **Mr McKIM** Firstly, thanks for the opportunity to appear before the committee. I thank all of the members, except for Mr Best, for the respect that they have shown me during this hearing. I again say that I believe there is potentially manslaughter or murder happening in hospital wards and palliative care wards around the country, and I know of no reason why it should be any different in Tasmania than in the rest of Australia. We potentially have a circumstance on our hands here that is similar to that which led Parliament to be recalled to deal with matters associated with abortion. Remember, Parliament was recalled and sat late into the night because of the urgency of that situation. I submit very strongly that the committee needs to urgently seek legal advice from the Solicitor-General on whether the current practice, current AMA policy, actually endorses manslaughter.

Mr WHITELEY - We will ask them after lunch.

Mr McKIM - I hope you do. My motivation for bringing this bill in is to try to do something about the suffering and indignity that is being endured on a daily basis by some Tasmanians who suffer from a terminal illness. Even palliative care doctors who oppose voluntary euthanasia have admitted that palliative care cannot and does not relieve intolerable pain and suffering in all circumstances. They claim that it does in most circumstances, and I have no reason to doubt that, but even palliative care experts who oppose voluntary euthanasia admit there are some terminally ill patients that just cannot have their intolerable pain and suffering addressed by palliative care. It is those terminally ill Tasmanians that I seek to provide with an opportunity to choose to die a more dignified and less agonising death. It would be good for them, good for their families, good for all the doctors involved and it would be good for the Tasmanian community which overwhelmingly supports law reform in this area.

CHAIR - Thanks, Mr McKim.

THE WITNESS WITHDREW.

Professor RAY LOWENTHAL AO AND **Dr CHRIS MIDDLETON** WERE CALLED, MADE THE STATUTORY EXAMINATION AND WERE EXAMINED.

- **CHAIR** (Mr Finch) Thank you very much, gentlemen. We very much appreciate giving up your time to join us today.
- **Dr MIDDLETON** Thank you very much to the committee for inviting us to make this presentation. We are from the Tasmanian branch of the Australian Medical Association. Firstly, we would have to say that we don't believe that dignity equates to euthanasia. We have difficulty with the concept that all of these bills that permit doctors to kill patients seem to be tied up somehow in the name of dignity. We don't believe that dignity is equivalent to euthanasia and we don't believe that if bills such as this are not available, or are not law, then patients necessarily die without dignity.

We think it is disingenuous to link dignity and euthanasia together but it seems to be the common practice. 'Dying with dignity' has almost become a euphemism for euthanasia. We note the facility in Switzerland is called Dignitas. We think it's a corruption of the word to use it in that context but it does seem to be common parlance, so I think it's important to make that point to start with.

We seem to have been here before - not myself personally, but certainly Professor Lowenthal has. There was an inquiry in 1997 and AMA Tasmania made a submission to the Parliament of Tasmania on the need for legislation on voluntary euthanasia at that time. The Community Development Committee reported its findings in 1998. I hope members of the committee have had a chance to read our submission because it makes considerable reference to the findings of the Tasmanian parliamentary report of 1998. To make it straightforward, we listed the main findings on page 2. I think all of those findings are important but perhaps I could quote from paragraph 10 onwards:

'The committee found that the legislation of voluntary euthanasia would pose a serious threat to the more vulnerable members of society and that the obligation of the State to protect all of its members equally outweighs the individual's freedom to choose voluntary euthanasia.

From the evidence presented, the committee found that in the majority of cases palliative care was able to provide optimum care for suffering patients. The committee recognised that in a small proportion of cases palliative care was ineffective in relieving all pain. However, whilst regrettable, this was not sufficient cause to legalise voluntary euthanasia.'

The committee went on to say:

'There is a need for greater resources to expand and improve the quality of palliative care services.'

This was in 1997-98 and since then, the AMA would contend that palliative care services have improved and there are more and better educated health professionals available to deliver palliative care in Tasmania than there were when these findings were made.

From our submission you will see that we believe the previous submission made by Professor Lowenthal on behalf of the AMA in 1997 - which appears at appendix 2 - is just as relevant as it was then, with the exception that there have been some changes since then. At the time that submission was written there were few, if any, places in the world where euthanasia was legal, but that has changed somewhat - and we will look at some of those changes in a moment.

You will see that the Federal AMA made a submission to the Senate Legal Constitution Affairs Committee inquiry into the Rights of the Terminally III (Euthanasia Laws Repeal) Bill 2008. That bill is looking at reinstating the Northern Territory's bill from 1997, which was struck down by Federal legislation. It is my understanding that that bill is still awaiting a reading in the Senate. In appendix 3 you'll find the Federal AMA's - our national body - submission to that process.

We don't believe that the current inquiry into the Dying with Dignity Bill 2009 is sufficiently at variance with previous inquiries into the question of euthanasia to require a complete re-examination of all of the well-rehearsed arguments for and against euthanasia. They are all listed in the committee report from 1997 and our response to all of those points raised in that initial committee report are listed in our original submission from 1997.

In short, the AMA does not believe that a bill such as this is necessary. Palliative care continues to improve. In jurisdictions where bills such as this have become enacted, in fact, the provisions are hardly ever used. If we look at the experience in Oregon, for instance, where they have had a bill with a similar name to this for some years now, it transpires that only about one in 1 000 Oregonians - I am assured that is the term - make use of the provision, so you would have to ask why you would wish to bring in a law into Tasmania which takes account of an occurrence that occurs 0.1 per cent of the time.

- **Ms FORREST** If it is 0.1 per cent of the deaths, how many Tasmanians are we talking about a year?
- **Dr MIDDLETON** I should be able to tell you to the absolute numbers how many people die in Tasmania every year but I can't. Do you know?
- Ms FORREST I think it is about 2 000 but I'm not sure.
- **Prof. LOWENTHAL** I have heard an estimate that if it is the same rate in Tasmania we would be talking about two or three deaths a year. That would be about right. So we would be legislating for two people per year.

Ms FORREST - Thank you.

Dr MIDDLETON - The argument that you could put up then, based on that, is that if it is only 0.1 per cent, what is your possible objection because 999 times out 1 000 there will not be any problem so there will be no issue there, will there? But the difficulty with legislation of this sort is it entirely changes the doctor-patient relationship. It poisons the relationship, in our view. The pre-eminent role of the doctor is as a healer and there is an old saying that the role of the doctor is to cure sometimes, to relieve often and to comfort always.

The raison d'etre of doctors is to comfort the patient. We do not see ourselves as the executioners of our patients and we think a bill such as this will change the dynamic and the way that patients regard their doctors. Patients will come to distrust their doctors if they think that the doctor might in fact be able to order their demise. We know that when the Northern Territory bill was enacted for a brief time in 1996-97 it was very difficult to get the Indigenous population to turn up at the local hospital because they were very anxious that the doctors would be do away with them.

So, in our view, legislation such as this goes against what it means to be doctor. We think that if legislation such as this comes in, then perhaps you should be finding someone else to do the job, frankly. We do not see this as a function of medical practice and, indeed, it has not been, as far back as Hippocrates. It is interesting to see that legislation of this sort is generally brought forward by fit, educated, middle-class people with personal autonomy issues rather than those who you would think would be mostly likely to be in favour of it. There are not any disabled groups calling for euthanasia. For people who are much less fit than the rest of us, you would think that perhaps their lives are not quite as worth living as ours might be, but they do not take that view.

Ms O'CONNOR - Sorry, Dr Middleton, can we just get the terminology right? We are not talking about euthanasia, we are talking about voluntary euthanasia.

Dr MIDDLETON - Correct.

- **Ms O'CONNOR** You have said euthanasia a number of times and I think it is important that we are very specific about the bill that we are talking about and its provisions.
- **Dr MIDDLETON** Right. When I say 'euthanasia' in this context what I mean is a doctor putting a patient to death after the patient has asked for that service.
- **Ms O'CONNOR** Because the patient has made a choice to seek euthanasia. Euthanasia might be a situation where a doctor determines, as is possible under the law in the Netherlands where you have involuntary euthanasia, once a board of ethics has decided that that patient is beyond help basically.
- **Dr MIDDLETON** Sure. So by euthanasia I will clarify that I mean voluntary euthanasia incorporating, if you wish, physician-assisted suicide, which is how that service is delivered in both Oregon and in Washington State.
- **Ms FORREST** And you would agree that this bill is what this is about: physician-assisted suicide?
- **Dr MIDDLETON** Well, not in the way that it currently exists in the Oregon and Washington situations, because the way it is done there is that the physician actually writes a prescription for usually a barbiturate something like Seconal or Nembutal and then it is up to the patient to actually take it. On reading the current bill it would seem that the physician can be a fair bit more active -

Ms FORREST - At present.

- **Dr MIDDLETON** Yes. It isn't actually stated how the death is to be brought about in the bill. It seems to suggest in fact more than suggest that it would be a much more active process than the simple provision of a prescription.
- Ms FORREST That's right; administration is part of it.
- **Dr MIDDLETON** Sure. I was just saying that disabled groups and those whose lives the fit, well-educated middle-class types might consider not quite as worthwhile as perhaps you might think, do not take that view, and if you are interested you could have a look at notdeadyet.uk for those sorts of views if you wish to look at what fairly vocal disabled people have to say about the provision of euthanasia or voluntary euthanasia/physicianassisted suicide.

The major point I think that was made in the previous Tasmanian parliamentary committee was that they could not find a way to make euthanasia/voluntary euthanasia et cetera work safely. They thought that it really was not something that you could bring in with sufficient safeguard, even if you were of such a mind to make it safe for the entire community, especially those who are more vulnerable and not particularly articulate in these regards.

So for all of those reasons AMA Tasmania does not support the Dying With Dignity Bill 2009, and I am happy to take questions. Perhaps Ray wants to add to what I have just said.

Prof. LOWENTHAL - Thank you for inviting us to be present here and to make a submission to you. My role in this is that, as it happened, in 1997-1998 when the previous hearings were held, I was then the President of the AMA Tasmania, as Chris is now, and I am still involved with AMA affairs, so it seems to be largely a going-over of old ground again.

At that time the AMA was very much against voluntary euthanasia in the sense that we discussed it, and I would like to point out that it is not just the AMA's view. The view that this is an unethical process for medical practitioners to be involved in is virtually the unanimous view of all the major medical associations around the world, including the World Medical Association, the American Medical Association, the British Medical Association and the Australian Medical Association nationally. These are all organisations which have given very great and detailed thought to it, and if you go to their web sites - and we have to some extent quoted them in our submission - you can see the depth they have gone into in considering all this.

We of course recognise that there are diverging views. There are a number of medical practitioners who themselves have opposing views, but there is something like I think 100 000 doctors in Australia, so it is no surprise that a small number of those would take a contrary view to the majority, but the overwhelming opinion of all these medical associations and members has been that it is an unethical procedure. Indeed, there was an interesting event in the UK a few years ago - I think in 2005 - where the British Medical Association has a policy that motions that are moved at their annual meetings become their policy and a small group of committed physicians took over the 2005 annual meeting of the BMA and passed a motion to say that the BMA should be neutral about the matter and not take a stand either for or against it. When the general body of

the membership became aware of it, the motion was re-put to the 2006 meeting, which attracted a record number of members, and they then reverted to their previous position, which is that the BMA is opposed to voluntary euthanasia. The reasons for this are manifold and Chris has given many of the views, but I am concerned about several things: first of all, I say it is unnecessary in the sense that it would be something that would be used by a very tiny number of people and there is an old legal axiom - I forget the exact terminology now - that making legislation for extreme cases is bad legislation because you put up a situation where, from the doctor/patient point of view, I would very much fear there would be a poisonous atmosphere. There would be so many things that are unsaid and vulnerable patients would be worried that their doctor may not act in their best interest.

We are talking about voluntary euthanasia, but we know in the Netherlands that this has crept into involuntary euthanasia. Even though the members of the committee are well aware of what we are talking about, there is still a widespread misconception in the community as to what we are really talking about. There was a letter in today's *Mercury* about somebody who expressed themselves to be in favour of euthanasia for demented people, but this legislation, as I read it, does not allow a demented person to be put to death at all, even if they had expressed that view years before. The legislation, quite rightly, has got the safeguard that somebody has to voluntarily request it, and repeatedly request it, and they have to be in a position where they are, at that time, dying.

If you go out in the community and ask people, 'Are you in favour of euthanasia?', or, 'Are you in favour of somebody who is suffering intolerably being put to death?', people often say 'yes'. It is often, I would contend, because of a misunderstanding of what it is all about, as is evident in today's paper, which is one of many.

To speak a little from my own personal experience; as you know I am a cancer specialist and I have dealt with many patients over the years who have ultimately died of their disease. It is a remarkable thing that, in all these years, I have almost never been asked by anybody whether I could do something. Occasionally, but still uncommonly, I have been asked by relatives of patients, 'Can't you do something, doctor?', meaning could I not speed the process up for the sake of relatives. Sometimes patients will say to me, not that they want me to do something, but, 'I wish it was over for the sake of family', because they do not like to see the family suffer - this is particularly elderly women - and I am very concerned that people in that position might be persuaded to request euthanasia for the sake of somebody else rather than their own sake. You can readily see, I think, that pressure might be put on people in a vulnerable position by relatives who would not always be acting in the best interests of the person who is dying. So I am very concerned.

To my way of thinking, this is not the way to go about the problem of ensuring that patients who are dying die with dignity. The way to ensure patients die with dignity is to have their physical needs addressed, their mental and emotional needs addressed and to die in comfort, most preferably with a family in attendance. This is not the same as having somebody being put to death after they have made a request. So, again, I would emphasise that dying with dignity does not mean euthanasia. Most people die with dignity and they do not use euthanasia.

CHAIR - Chris, is there something else you want to add?

Dr MIDDLETON - One final point. There have been multiple inquiries into euthanasia legislation around the world. We had the one from Tasmania, there was one at the same time in South Australia, the House of Lords made a very thorough examination of the situation in about 1994 and one gets the feeling on reading through the papers that quite a few of the members of the committee went into those committees thinking that there ought to be some sort of law reform here, we really ought to be able to manage this better - in other words, we ought to be able to find a way to make voluntary euthanasia fit in to the scheme somehow - but on looking into all the complexities all of these inquiries have come away saying that it is just simply not possible to make the situation safe. To quote from the House of Lords:

'We do not think it is possible to set secure limits on voluntary euthanasia. We took account of the present situation in the Netherlands, indeed some of us visited that country and talked to doctors, lawyers and others. We returned feeling uncomfortable especially in the light of evidence indicating that non-voluntary euthanasia was commonly performed. Furthermore we concluded that, if legalised, it would be virtually impossible to ensure that all acts of euthanasia were truly voluntary and hence that any liberalisation of the law in the UK could not be abused. We also felt that vulnerable people, the elderly, lonely, sick or distressed, might feel pressure. whether real or imagined, to request early death. Our decision was also influenced by the outstanding achievements of the palliative care movement in the UK'.

Other inquiries since that time have come to a similar conclusion, and here we are having another inquiry into the same question. We do not think that anything has changed since these inquiries and our view remains the same as before.

- **Mr WHITELEY** About an hour ago the author of the bill, Mr McKim, gave his evidence and the reasons he felt that the committee should recommend its support. One of the staggering claims that he made was that murder and manslaughter were happening pretty well every day in hospital wards and palliative wards across Australia. I said I would ask you about this. You have gone some way in your submission on page 9 to address a similar sort of survey. He provided and tabled what he said was empirical evidence from a 2003 survey where 36 per cent of surgeons who responded said that they were administering overdoses of drugs with the intention to hasten death. It is a big claim to say that murder and manslaughter are happening in hospital wards and palliative care wards across Australia. What is the AMA's response to that claim?
- **Prof. LOWENTHAL** I think that is entirely incorrect. It just does not happen like that. If I can I will explain to you why I think this is a misleading statement. First of all, if you imagine a situation where a dying patient is prescribed morphine every four hours and a nurse goes along and gives the four-hourly injection and half an hour later the patient dies. Many nurses or people who are not familiar with dealing with dying patients will think that they have killed that patient by that injection, whereas in fact it was the normal process of dying. Similarly, if a physician orders morphine or some other appropriate medication to control pain or suffering for a patient who is in the process of dying, and they then die, people may fear or believe or feel that they have caused the death of that patient whereas in fact all they were doing was ensuring that the death was comfortable.

I have not read this recently, but I am aware of this paper from some time ago - a lot of it is talking about administering morphine and similar drugs while patients are in the process of dying. It is possible it is quite conceivable that those injections may bring the death of a dying patient forward by a few hours or a day or two. This is not what we are talking about in terms of voluntary euthanasia, though. It is the intention of administering the opiates in those situations. It is for the patient's comfort; it is not to cause their death. What we are talking here in voluntary euthanasia is the bringing about of the death of a patient who has a terminal illness but is not necessarily in the process of dying, bringing that death forward by some considerable time. So I think there is a misunderstanding there. I can assure you that 36 per cent of deaths in the Royal Hobart Hospital are not caused by murder or manslaughter.

- **Mr WHITELEY** No, it was 36 per cent of surgeons who said they had participated. I think your connection to this is on page 9 where, in a recent paper in the medical journal, it was alleged that 1.8 per cent of all Australian deaths were brought about by clandestine euthanasia and that in up to 30 per cent of deaths a medical end-of-life decision hastened or influenced death. Your submission which I welcome because I would not think this would be happening in our hospitals says that, to anyone involved in the care of the dying, the suggestion that nearly one in 50 Australian deaths is brought about by a physician injecting the patient with poison, for that is what euthanasia means in the current debate, is completely preposterous. So I just want to give you an opportunity to respond to what I think could be easily taken by the public, if just read in isolation, that suddenly that does put into question the trust relationship between a doctor and their patient. So I wanted you guys to put on the record what you felt about those comments.
- Prof. LOWENTHAL So have I responded sufficiently?
- Mr WHITELEY I think so, and you are claiming it is preposterous.
- **Mr BEST** Looking at your submission, you do put a very strong emphasis on palliative care. What are your feelings about the knowledge of people out there in the community who are facing terminal illness? Do you think probably there could be better education and knowledge about palliative care, or do you think it is sufficient?
- **Prof. LOWENTHAL -** Obviously there is always room for more education. The one major thing that has changed between the 1997-98 inquiry and now is that palliative care services in Tasmania have improved but there is always room for further improvement. I commended the various governments over the years for having put more money into palliative care. We now have a number of palliative care physician specialists and a considerable number of palliative care nurses who work in the community and visit people at home. Obviously there has been inevitably a greater understanding of what palliative care can achieve. Nonetheless, it is particularly important that the message get through outside the bigger centres, the smaller towns where GPs may practise, to some extent, in isolation. The more funds that can be put into palliative care, the better.

Education is very important but it is happening. It never can happen enough. There is a lot of room for education, not only for GPs but also nurses and all other health care workers and the general community as to what palliative care can achieve. One of the best things that has happened in palliative care has been the ruling that anyone can be referred to palliative care by anyone. You do not have to go through a specialist. You

do not even have to go through a GP. A patient themselves or a relative of a patient can ring up a palliative care service and ask for that palliative service to provide assistance. I think that is a tremendous innovation, but there is always a need for the public to be aware of this.

- **Mr BEST** So do you think that there could be a bit of ignorance? Certainly in the context of someone facing terminal illness, people in that situation are vulnerable and would be quite emotional. Do you think there is this fear about suffering and maybe not even, in some cases, wanting to look at the issue of palliative care perhaps?
- **Prof. LOWENTHAL -** Yes, of course. Again, this is one of the things that has improved a lot in the last few decades, that people are now much more prepared to face up to death. When I was a medical student which was a very long time ago, about 40 years patients who had a lethal illness were never told of that. If you had bowel cancer that caused an obstruction they were just told they had a blockage. If you had a lump in the breast you had to have your breast off but you never told anyone what it was for. It is crazy when you think back; people obviously knew and there was a whole lot of subterfuge going on, 'I know what you're not telling me, but I won't admit that I know', and so on.
- **Ms FORREST** Even nurses wouldn't. We would talk about the 'big C'. We wouldn't even say 'cancer'.
- **Prof. LOWENTHAL** So the attitudes have changed a lot, and this has helped, nonetheless there are still many people who think palliative care is synonymous with dying in the very short term. I often have to reassure patients that it's good to get the palliative care service involved in the early stage in their illness so that they can get to know each other and they can provide palliation or relief of symptoms even at a stage when there is no immediate prospect of death. So there is a need to educate the public.
- **Mr BEST** I appreciate that professional advice because it's important for people in positions of responsibility, say parliamentarians, if somebody comes forward with a terminal illness then it's incumbent upon us to at least say to people, 'There are certainly options of seeking palliative care'. As a matter of fact, it is a duty of care to provide that information to people.
- **Prof. LOWENTHAL** Absolutely.
- Mr BEST What would your thoughts be, then, if you know that wasn't provided?
- **Prof. LOWENTHAL** I don't know how it wouldn't be provided. I actually have a palliative care qualification but I don't class myself as a palliative care specialist. All the oncologists in the State work very closely with the palliative care doctors. For example, I have a meeting once a week with the palliative care nurses where we go through a list of about 120 patients that we are mutually caring for, and we discuss the various issues. Palliative care is very well known amongst the hospital doctors, and I can't see there would be situations where patients are not referred.
- Mr BEST The question you ask about why somebody wouldn't, or how the situation didn't arise, is in relation to the person who is putting the bill up. Mr McKim has talked about

a constituent, Mr Cordover, who was facing a terminal illness. He explained to the committee that there was no discussion with him or the constituent about palliative care, which I found odd but obviously your view is that it ought to be discussed.

Prof. LOWENTHAL - Certainly.

- **Ms O'CONNOR** Do you think a politician needs to advise their constituent about palliative care options? That's a matter for the doctor and patient, isn't it?
- **Prof. LOWENTHAL** It is a matter for doctor and patient. I am just surprised that it wasn't discussed, but of course I don't know the details. As I mentioned, it is open now to the whole general public; they don't have to go through their doctors to contact the palliative care service. You don't need a politician or anybody to do it; you can do it yourself.
- **Ms FORREST** I know you are opposed to the intent of the bill. It is basically giving doctors an exemption from the Criminal Code, which they don't appear to be asking for. It has been brought to my attention by a number of people, legal and medical, that there are problems with things like definitions the lack of requirement for the doctor who is involved in the care of the patient to be a Tasmanian doctor, for example. There is no requirement for them to know the patient for any length of time or anything like that. There is no discussion or suggestion around the use of advance directives, for example. Clause 8(1)(c)(i) states that one of the medical practitioners that the patient has to see must hold prescribed qualifications, or have prescribed experience, in the treatment of terminal illness from which the person is suffering. So there is a whole range of issues that have been identified as not being particularly clear.

If the bill was to be supported, are there areas where it could be improved to clarify some of those issues, or do you think they are issues at all?

- **Prof. LOWENTHAL** There is one thing that you've mentioned. I notice that the bill was very careful to say it can only apply to people who are residents of Tasmania, to obviously stop suicide tourism, as they call it in the United Kingdom where people are flying to Switzerland to take advantage of this type of legislation. But maybe there should be similar legislation so that the doctors themselves have to be resident Tasmanians, otherwise you may end up getting some fairly unpleasant publicity, I guess.
- **Ms FORREST** What about the requirement to have known the doctor for a length of time, to have been a patient of that doctor for a length of time?
- **Prof. LOWENTHAL** That was one of the issues that came about with the Northern Territory legislation when it was in place, that it was difficult to define 'doctor'. There are a whole lot of issues there. One of the issues is about the psychiatric requirement where you need a psychiatrist to say the person is of sound mind. In the review that was done of the Northern Territory legislation it was pointed out that, for the patients who wanted to take advantage of the legislation, the need to see a psychiatrist was just seen as a hurdle to jump over and they were, in a way, coached to say the things that would make them seem as if they were not depressed, even if they were. There is a concern that if a psychiatrist is only to see a patient on a single occasion they may not get the full extent of an understanding of what is really going on in that patient's mind.

What you point out is really one of our major points, that no matter how carefully crafted legislation of this kind is - and I do acknowledge that this bill is more carefully crafted than many I have seen previously - you still cannot legislate to prevent all potential abuses.

- **Ms FORREST** I want to take that point a bit further. One of the issues I had when this bill was first tabled, and regardless of my personal view either way on the bill, was that concerned with the safeguards in and workability of the bill. I did a flow-chart myself; I went through the bill and produced a flow-chart that was my understanding of how it would work. You start in the top left-hand corner -
- Mr WHITELEY I've checked it and it's actually right.

Ms FORREST - Thank you.

- Mr WHITELEY I found it very intriguing.
- **Ms FORREST** Safeguards abound, I would suggest. However, the point I would look at is whether, in reality, it will work and, as medical professionals, how realistic is it that someone would be able to jump through all of those hoops and maintain mental competence until to the end, with a terminal illness, suffering intolerable pain and possibly having medications to relieve that pain? On the north-west coast, for example and this bill needs to be good for the whole State to get a psychiatrist you can wait weeks, if not months, particularly for a non-urgent case as opposed to a psychotic crisis, and even to access a palliative care specialist or a doctor who is specialised in that area. It is not clearly defined in my mind how that person should be qualified to fit the bill. As medical practitioners who work in the area, if I really wanted to avail myself of this and I lived in Smithton, would I have any hope?
- **Dr MIDDLETON** I think you have answered the question really. If you have to have a scheme as complex as this to navigate this piece of legislation, then the chance of it working in the real world is remote.
- Ms FORREST That is one of the reasons I did it. I was really concerned about the level of safeguard.
- Mr WHITELEY We are impressed that you did do it.
- **Ms FORREST** Thank you. It was in my week of recovery from a minor procedure. But, at the end of the day, safeguards are really important and by putting all those safeguards in you exclude a range of people, like people with psychiatric illness, people with dementia, people who have mental incapacities, for whatever reason, acquired brain injuries, stroke and whatever. All those people are excluded and so here we have a bill that is really complicated with lots of safeguards, but can it work?
- **Prof. LOWENTHAL** I cannot see it working; this is even more complex. Again, I just make the point that it is clear that Mr McKim has taken note of the criticisms that were made of previous bills and has therefore put in a lot of safeguards and quite rightly so, but having done so he has made it so complicated that it almost cannot work. It just

shows that no matter how careful you are about putting in safeguards there is no amount of safeguards that can properly safeguard society from a potential abuse.

Dr MIDDLETON - I think it is also important to realise that doctors are fallible and don't always get things right. If you look at this paper regarding the seven deaths in Darwin, case studies under the Rights of the Terminally III Act, which was in the *Lancet* from 1998, seven patients made use of the Rights of the Terminally III Act and four died under it. According to the paper in the *Lancet* three of those patients were socially isolated and four had symptoms of depression. The authors, who included the general practitioner who was most prominent in facilitate use of the act, cautioned - this is someone in favour of and who was using it - that the assessment of depression is difficult in the terminally ill and accurate prediction of prognosis is subject to disagreement. There are clear limitations of the gatekeeping roles of the medical specialists and psychiatrists in the Rights of the Terminally III legislation.

What we are saying is the people who are making these decisions who are crucial to this role - the various medical assessors - aren't guaranteed of being able to accurately diagnosis depression in the terminally ill and when the patients ask for prognosis we often tend to be wrong quite considerably, I think it would be fair to say, don't you agree, Ray?

- **Prof. LOWENTHAL** There are many surveys done of doctors regarding accuracy in predicting the time course of an illness and it is notorious that doctors are wrong.
- **Ms O'CONNOR** I want to go back to the *Medical Journal of Australia* paper because the issue here with palliative care and the relationship between doctors and patients towards the end of life in terms of relieving suffering is intent, isn't it? If the intent is to relieve suffering -

Prof. LOWENTHAL - Exactly.

- **Ms O'CONNOR** but the doctor administers the medicine in the full knowledge that the effect may be to shorten life, and of 992 eligible general surgeons who were sent this questionnaire 682 responded, so it is about a 70 per cent response rate. Question number 2 is, 'Do you believe that there are any circumstances in which it is morally acceptable to give a terminally-ill patient sedatives or analgesics by slow intravenous infusion in doses greater than those required to relieve symptoms with the intention' that word in bold in the *Medical Journal of Australia* paper 'of hastening a patient's death?'. The affirmative responses came back at 54.1 per cent. So how does that sit, Professor Lowenthal, with your view that is not an act of involuntary euthanasia?
- **Prof. LOWENTHAL** Involuntary? There is more than one interpretation of that.
- **Ms O'CONNOR** To be fair, I am absolutely certain that the doctors who believe this or who have taken such a course are acting out of compassion and a desire to relieve terrible suffering, but the AMA must surely understand that it is happening?
- **Prof. LOWENTHAL** People are saying they would agree with it happening, they are not saying they are doing it.

- **Ms O'CONNOR** Well, 4.2 per cent who responded agreed that they had granted an unambiguous request from competent patients. Question 3 asked, 'Have you ever received a similar request' that is a sincere and unambiguous request 'from a competent patient for you' these general surgeons 'to administer a lethal dose of a drug?', and 27.4 per cent said yes and the follow-on question the hard question have you ever granted such a request by giving a bolus lethal injection presumably that is a single thump of some sort of medication 4.2 per cent of the general surgeons who responded agreed that they had assisted the suicide of their patient on request.
- **Prof. LOWENTHAL** This is like legalising burglary because it occurs; just because people do something that is wrong does not mean you should legalise it.
- Ms O'CONNOR Is that not an act of manslaughter, at the very least?
- Prof. LOWENTHAL Yes, I think it is.
- Ms O'CONNOR And it is happening within the profession.
- **Prof. LOWENTHAL** What they are saying is that they may have done it once. A small proportion of doctors, surgeons and you are also talking about people going back into the past, many years before palliative care was properly available. If you asked, 'Have you done this in the last few years?', I would be very surprised if the figure was anything like that. Even if it happens, that it is not a reason to make it legal.
- **Dr MIDDLETON** This paper was published in 2001. All the practitioners are surgeons, we do not have any idea of their age or how long they have been practising. I have not had a chance to read this paper, but just on a quick look through, I don't see that, so say, perhaps, once back in the 1960s, I gave someone a shot of morphine because I did not know what else to do. There is no real information as to how far back this goes and in what sort of circumstances. This is asking an unselected group of surgeons a question about something that may have happened 'ever' means once in a professional lifetime covering thousands of patients. It is hard to get a handle on how big this issue is now by quoting an historical paper with those sorts of limitations on it, even if the surgeons accurately remember the events about which they are asked. I think, as Ray pointed out earlier, with a lot of inpatients receiving regular narcotics around the time of death, having just administered the narcotic and seeing the patient expire sometimes they think, 'Oh, I did that'.
- Ms O'CONNOR How can you be absolutely sure they didn't do that?
- **Dr MIDDLETON** You cannot, but if they gave what was written-up on the chart, then it is highly unlikely that they took independent action; that is the point.

So for you to say that this is happening now in our hospitals -

Ms O'CONNOR - I am asking if it is.

Dr MIDDLETON - From a retrospective analysis of 600 surgeons over God knows how long their professional lives were when the question was asked. Retrospective analyses such as these can often be made to give you any answer that you want. I would have to

say that if there were perhaps a proliferation of these papers then I might think that perhaps this has been more of an issue than I thought it was.

This is now all anecdotal evidence - the Simone one - people are talking about experiences in their own lives. We are not talking about a proper prospective study where you set the parameters, ask the question, wait until the end of the study, and then get the answer out; you are asking for an anecdotal retrospective view.

So if I can be anecdotal and retrospective; I have personally dealt with a lot of dying patients and have been involved peripherally in the care of a lot of dying patients, and I do not know anybody who was 'knocked off' intentionally by their doctor. So maybe I would be one of the 300 surgeons, if I were a surgeon, who responded in the negative.

Doctors talk, and if this is not something that is a common topic of conversation - maybe doctors do not own up - but we talk pretty much about everything else.

- Ms FORREST Including mistakes?
- **Dr MIDDLETON** Yes, we talk about our mistakes all the time. It is an interesting paper, but it does not pass as a scientific paper. It does not pass muster because it is retrospective and anecdotal.
- **Ms O'CONNOR** It is probably worth having a look at some of the explanations of the methodology. It was an anonymous self-administered mail-out questionnaire. It went through an ethical approval process. Some of the doctors who responded volunteered comments and I just want your response to this comment:

'I have frequently used large doses of morphine, previously heroin, to hasten death. I can't see the ethical difference between this and a bolus injection in a fully-informed patient but simply would not be capable of the deed, myself.'.

- **Dr MIDDLETON** Okay. What would you like me to say about that? Do I agree with that?
- **Ms O'CONNOR** No, I am sure you do not, but do you acknowledge that this is a case where a general surgeon admits to using large doses of morphine to hasten death? Do you acknowledge that is a practice in medical palliative care today?
- **Prof. LOWENTHAL** This surgeon has used heroin which tells us that he has come from the UK where heroin has been legal, but it is not legal anywhere else in the world. The other point to make is that surgeons are not palliative care specialists, and I am sure the situation is very different today. This obviously goes back some considerable time. Again, I make the point that just because burglary takes place, you do not make it legal. So, the fact that this surgeon has been doing this does not make it right or mean that we should legalise it.
- **Ms O'CONNOR -** Professor Lowenthal, you said that in your view the law is unnecessary because of the small number of people who have used it in Oregon 341 people. Would you acknowledge though, for those 341 people, there was a great comfort to them in

being able to exercise their personal autonomy to choose the timing and manner of their deaths if they were suffering from a terminal illness? That while it only might be a very small number of people, these are the people for whom palliative care is not providing relief?

Prof. LOWENTHAL - Yes, I am sure it is so for a small number of people. There have been reviews of the Oregon act, and one of the reviews made a point about how difficult it is to recognise whether patients are not truly depressed and that a significant proportion of people who had their death expedited by the act almost certainly were depressed. So it is an issue as to whether you think that is the correct thing to do: whether it is right for a law to allow people who are depressed and who, with appropriate treatment, may become less depressed and may find that the rest of their life is worth living, or whether it is correct to hasten their death.

I think you are talking about legislation which, in my opinion, is dangerous because it is legislation for extreme cases which is bad legislation for the general community.

- **Ms O'CONNOR** So, as a compassionate society, how do we respond to those individuals who have been diagnosed with a terminal illness and for whom palliative care is clearly not providing relief? Ray, you are a beautiful human being and you must have been there at so many people's bedsides and there must be cases where palliation is not working.
- **Prof. LOWENTHAL** It works in nearly every case in terms of pain. What people fear most about is that they are going to have intolerable pain. In fact intolerable pain, these days, is almost never a situation. It is notable that of the people who made use of the act in the Northern Territory, nobody made use of the act because of pain. They used it because of mental suffering, mental anguish, and anticipatory pain; they were concerned that they might suffer more in the future, but it was not because of present painful suffering, it is existential suffering.
- Ms O'CONNOR But this bill talks about intolerable pain and suffering.
- **Prof. LOWENTHAL** They are almost certainly not going to get intolerable pain because palliative care is so good. Intolerable suffering is a subjective thing. You cannot say that people do not have intolerable suffering, but in virtually all the cases I deal with, it is possible to make people calm and free of apparent intolerable suffering with various drugs. I cannot see inside people's minds and they might say otherwise, but from the exterior, people these days seem to be calm and comfortable. Of course, not immediately: I have seen on many occasions people come along with terrible pain and say, I just want it over with, but if you get their pain under control, then they do not say that anymore.
- **Ms O'CONNOR** Dr Middleton, we were talking before about how there are disabled groups in the UK which are very concerned about this, and one of the questions I have been putting to people who come before the committee is, do you accept that the law, as it currently stands, discriminates against people with physical disabilities because, if I am diagnosed with a terminal illness, I can take my own life or try to take my own life. I am physically capable of doing it and that is not an illegal act. However, as Justice Underwood found in the Godfrey case, if you are physically disabled and you

want to take your own life then you are going to need to make someone complicit in that act, so the law as it stands discriminates against people with disabilities.

- **Dr MIDDLETON** I do not believe that the law necessarily discriminates against disabilities; there is no law against suicide. If your point is that if I have no arms or legs, I can't commit suicide because it is very difficult to do that.
- **Ms O'CONNOR** Yes, or if you are so physically disabled by illness, like Robert Cordover with motor neurone disease.
- **Dr MIDDLETON** Sure. I do not believe that the law is necessarily discriminating. The law is not there to find a way for people to commit suicide. Suicide is not illegal but suicide is not something that is encouraged in our community. We are very concerned about suicide in our community. The number of people killing themselves at the moment is a topic of great concern to us all so I do not see why the law should be changed to make suicide easier for people, if that is your point.
- **Ms O'CONNOR** Maybe it is to stop people being in a position where they do take their own lives because they do not feel there is any other course of action when they are going down the path of death.
- **Dr MIDDLETON** I am not sure I follow your point there. With reference to patients in Oregon, there was a paper earlier this year in a medical journal, *Archives of Internal Medicine*, that looked at those patients, the one in a thousand, and found they used the act for reasons of autonomy or out of fear of possible future suffering rather than for present pain or unrelieved physical suffering. So we are talking about a small number of people and, even for those who choose it, it is not from dreadful pain and anguished death that are sometimes used to justify bringing in these voluntary euthanasia bills.
- **Ms O'CONNOR** One of the other things they found in Oregon was that people had the medication and took it home but did not use it. There was the comfort in knowing that it was there.
- **Mr GAFFNEY** Obviously people in the medical profession who believe in voluntary euthanasia believe that they are acting ethically that is their personal ethics. With the WMA and the AMA, is there any other issue that is ethically prohibited from that point of view?
- **Prof. LOWENTHAL** Heaps of things. Participating in torture and participating in the death penalty are two that immediately come to mind.
- **Mr GAFFNEY** Even though physicians are ethically prohibited according to these organisations, yet we have physicians in different countries and states involved in voluntary euthanasia, so how does this profession accept the personal ethics of physicians to do this sort of thing or why aren't they barred from their profession if it is ethically prohibited?
- **Dr MIDDLETON** You cannot actually perform voluntary euthanasia legally anywhere in the world except for Belgium, the Netherlands, Switzerland, Washington and Oregon, to the best of my knowledge. I think there might be one eastern block country, perhaps

Romania or somewhere, that also has similar legislation but outside of those you would be acting against the law, never mind against the ethics of the medical colleges.

- **Mr WHITELEY** So in Tasmania if you were found to be doing that it would be illegal and you would probably go to jail and you would be struck off?
- **Dr MIDDLETON** Certainly if you were found to have killed a patient then the Medical Council would take a dim view of that, as would the law.

CHAIR - Thank you.

THE WITNESSES WITHDREW.

Mr MICHAEL HARRIS, <u>Dr HEATHER DUNN</u>, <u>Dr HELEN CUTTS</u> AND <u>Dr MARGARET SING</u>, DYING WITH DIGNITY TASMANIA INC., WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

- **Mr HARRIS** I am president of Dying with Dignity Tasmania and we are an organisation with no religious or political affiliations. We have membership from all parts of the State, including the north-west. Our vice-president is Margaret Sing and Heather Dunn is a palliative care specialist.
- **Ms SING** Having read the transcript of the Launceston evidence and sat through all of the evidence today, except for the first half hour, I note that we are the only individuals providing evidence in favour of the bill at these hearings. You get a very biased view of what the general population might think about this bill from what we have been hearing today. So, on behalf of Dying with Dignity Tasmania, we would really like you to look at the evidence and I put 'evidence' in inverted comas that has been put to you because so much of it looks, to us, like opinion without any supporting evidence at all. In some cases, points of view were put forward in the face of a large amount of evidence to the contrary. One of things that is most concerning to us and the people who have read the transcripts from Launceston is that there are people who have put matters before this committee that are just plain wrong, and when a member of parliament, and I have to name him Mr Hidding has a submission that has substantial errors in it, it really is not very good. So we would like you, as a committee, first of all to test the comments being made to you as to whether or not it is an opinion without any supporting evidence or an opinion in the face of contrary evidence.

I was quite appalled by Dr Middleton and his claim that people who support this bill tend to be the fit and the educated with 'personal autonomy issues'. Who is Dr Middleton or anybody else to say what all of the Dying with Dignity Tasmania people are like or think? And who is he to claim that we have personal autonomy issues? There were a large number of other comments made at the Launceston hearings about people not knowing if they are answering the question. 'When they answer the question in all those opinion polls they don't even know what they're doing.' How arrogant and outrageous is that?

I promised I was not going to get wound up today, but in the face of some of the things we have heard it is very hard not to. I am involved in this issue for the same reason that I was involved in a lot of issues over the years, like the women's movement, equal opportunity and so on. I have had to sift and read through so many things that have been said about this issue that if you changed the word 'patient' to 'woman', 'Aboriginal person', or 'person with disabilities', it is exactly the same type of argument.

Mr WHITELEY - I don't think so.

Dr SING - Well, I will give some examples.

Mr WHITELEY - That is your opinion.

Mr GAFFNEY - And this is her opportunity to express it.

Dr SING - I will support it with argument as we go through.

The Dying with Dignity Tasmania submission covers a whole range of things and I guess those of you who have read it will raise some of those issues and both Heather and Helen will make comments that pick up on some matters particularly to do with palliative care so I will not deal with that.

I guess our key message would be: don't ignore the needs of the people that this bill is there to help just because there are so few of them. There are not many kidnappings in Australia but that doesn't mean we don't have legislation for it. It is just silly to say you don't need legislation for a few cases. Those people exist and they have very important needs, so please don't ignore them or shove them aside, as so many of the people we have heard and read about have done.

The other key area of the comments both today and in Launceston was that the 1998 inquiry still stands and nothing much has changed since then. There was some acknowledgment today of the changes in legislation and the legislation that has come in in Oregon, the Netherlands and so on, but we would say that there have been substantial changes since 1998. There have been changes in population and changes in attitudes to a number of things. The Parliament of which you are all members has brought in legislation - the Relationships Act - that 12 years ago we would not have seen perhaps, and other legislation, and we comment on that in our submission. There have been substantial changes since then.

The big thing that has been shown by the legislation overseas is that there isn't a slippery slope, the legislation is working effectively, and I will come to just one of the inaccuracies in the evidence in Launceston and that is the repeated statistic about the Netherlands that more than 1 000 people are involuntarily euthanased by their doctors. That was a figure from a 1990 report - the Remelick Report - in the Netherlands. They are still quoting that figure, taking no account of what has happened since then. I would like to table this - I don't have more than one copy. I kept coming across this figure 'more than 1 000' - is it true? No, it isn't. Things have moved along a lot since 1990. There are statistics in here, evaluation done on the Netherlands legislation.

For my own purposes I also wondered, 'Is it only happening in the Netherlands?' Well, no, it isn't, and we have heard some evidence of that today. I will also table a fact sheet from our South Australian counterparts about that, which has some further things to follow up on. The most recent document and research that I could find was published on 28 July 2009 and was about two decades of research on euthanasia from the Netherlands. There is no slippery slope but there are some things in there which I can't go into because of the amount of time we have.

We have also done a further analysis of the evidence given in Launceston. Just to pick up on a couple of major inaccuracies in Mr Hidding's evidence - we have actually done a paper on it but because it hasn't been through the committee I can't table that today - a claim that is quite common to the anti-euthanasia people is that Germany had euthanasia legislation; that euthanasia was permitted and legislated for in Germany. It was not; it was an order by Hitler. That claim is usually made in that sense of the slippery slope.

Mr Hidding's description of the Purdy case in the UK also wasn't accurate, but he then went on to make assumptions and interpretations of that which are simply wrong. He

indicates that the evidence of a groundswell of public opinion is based on a poll of 1 000 people; there are thousands of people who have been polled on this issue. He argues that the sanctity of human life principle is included in human rights charters. It isn't. The sanctity of life principle is distinctly based - and we heard it this morning from the Very Reverend Humphrey - on the notion of a God giving and taking away life. That is not what the UN Declaration of Human Rights and the International Covenant of Civil and Political Rights is based on. It is a civil right and does not depend on any notion of God for its effect. We have every belief that this particular legislation would not be against the UN Declaration of Human Rights.

I want to mention a couple of other points before I hand over to Dr Dunn. I made the comment about the type of arguments being used here that could be applied to all those issues of the 1970s. It's the paternalism, the 'we know best' attitude. I don't think there is any doubt about the compassion and care of the doctors you heard from and that we know about too, but it is still paternalism, it is still implying that they know best. There was a response by Dr McGushin to a question you asked in Launceston; he was concerned about the sufferer having the right to make the decision about it, which I found absolutely extraordinary. Once again, if you replace that with the word 'woman' or 'Aboriginal person' or 'person with disabilities', you see the paternalism for what it is. Not all paternalism has that positive face but a lot of it does, and there is certainly an indication in the literature that in numbers of cases in the Netherlands doctors are not getting specific permission because of the long-term relationships that they have with the patient and they are making that decision for them out of compassion. But we don't believe that is good enough. We want the right and the legal option here to be with the person concerned - that is, the person who is suffering. It shouldn't be a decision made by their doctor, their family or anybody else. We would like that clear legal option so that it is with that person.

We believe, and we have evidence in our document and in these other documents, that this legislative option is responsible, democratic and safe. A great deal of the opinion expressed this morning and in Launceston was that it isn't safe and people are going to have pressure put on them; that's another form of paternalism. So what are people going to do? 'Oh, my relative wants me to die now; all right, I'll just give up'. The assumption, once again, is an opinion based on nothing. I won't get wound up any more and hand over to Dr Dunn.

Dr DUNN - Thank you very much for this opportunity to speak to you. I must admit I am very nervous so my voice will probably flutter a bit. I was Dr Paul Dunn's predecessor in palliative care for a couple of years. Although I wouldn't class myself as a palliative care specialist, I do have a fairly close knowledge of what goes on and, even though I accept that there have been advances and improvements over the last few years, there are still areas in which palliative care does not have all the answers.

Let me state, first of all, how important palliative care is and that it still has a central role to play in caring for people who have incurable or terminal illnesses. I acknowledge that. I also would like to state quite clearly that the proposed legislation for assisted dying is not in any way in competition with palliative care. We see it purely as an adjunct, not an alternative, to palliative care. I would like to also point out that there is evidence that where these two coexist - in Oregon, for example - palliative care services

have improved because assisted dying is also permitted. I have no reason to explain why; it is just an empirical observation that this is so.

Having said that certainly palliative care is excellent but it does not have all the answers, I would like to turn to the answers that they do have and try to explain, in very simple terms, what this means to a patient who is undergoing the sort of intolerable pain and/or suffering that a lot of terminal people have. It seems that there is finally acceptance by everyone, even those opposed, that there are some people whose distressing symptoms cannot be controlled by palliative care. The most common form of helping these people is to suppress their symptoms by giving terminal sedation. I would like to just give you two scenarios, one of what happens now and one of what we would like to see happen if this legislation came in, just to see it from a person's point of view, not a statistical point of view. I am not quoting rules, regulations, statistics, or history; I am talking about people. I am a person who deals with people and I am telling you that this is what happens at a personal level.

Imagine a patient who has been through palliative care. Their symptoms haven't been eased, they're still distressed and they say, 'Please, I beg you, help me to end my life'. When they come to palliative care, they beg, and this is what does happen. If doctors say that they haven't been asked to help I'd suggest that maybe patients suss out their doctors as to whether they are compassionate and are likely to be responsive, and I think if you have had no requests maybe you are not coming across as a compassionate doctor. Anyway, they ask for this and you say, 'Sorry, we can't do it. Legally we're not allowed to do anything', and they say, 'In that case I refuse to eat and drink and I will starve and dehydrate to death.' You offer them IV fluids, you offer them a nasogastric tube. 'No, I refuse to have all that. I do not wish to continue with my life, so I will starve myself to death.' Then you discuss with them that all you can really do is give them adequate sedation to try to suppress their symptoms and the symptoms that will be associated with the dehydration process. So that is agreed, and then the whole thing comes into operation.

Now at this point the patient concerned will be quite upset and distressed to think that their relatives, friends and loved ones are going to observe them going through this process. They know that they're going to be lying in a bed, wasting away. They will be defecating in their bed or into napkins or whatever because they are not conscious enough to go to the toilet, and their relatives are going to see this, so that in itself is distressing. Then you have the relatives who come along. Someone needs to be with that person in case they die, so the relatives have to roster themselves so that someone is always there, because they fear they might wake up from their induced coma or suspended animation status and they want to be there with them. Someone certainly wants to be there with them when they die, because if they do not have someone there they will feel guilty forever after.

So this process goes on with relatives having this emotional see-sawing of being there the whole time, with the physical discomfort and exhaustion of dealing with this, and you must also take into account the feelings of the health professionals who are providing this service and how distressing it is for them too. So this person lies there. They are given mouth care and are turned frequently, and they usually moan when that happens. Whether they feel it or not it is hard to know, but they certainly moan and give the impression that they are feeling some sort of discomfort. They have a catheter to

collect their urine. As I say, they still have bowel actions, so that has to be cleaned up periodically. And then days or sometimes a couple of weeks later, they finally die, and that is supposed to be the best palliative care can offer and is considered by a lot of people, I assume, to be a dignified death.

What we are proposing with the current legislation under review is that a scenario would look a bit like this. A person has gone through the palliative care process, has not found relief from their symptoms, they have been through the process of being assessed by the medical fraternity and it has been declared that the criteria for ending their life is appropriate - they do fit that criteria - so then what would happen is that they would have a choice of where they would die. No doubt most people would prefer to die at home. They die at home, they choose the time of their death and which people they wanted around them. Those people would be able to be there to give them a hug, to say their last farewells and to hold them while they either took their own medication or were given an adequate injection by a doctor who was present, and they would quietly pass away and that would be the end of it. That is what we consider and what we are lobbying for as a dignified way for people who wish to make that choice to die. As I say, that epitomises what we consider to be dying with dignity, but the first scenario we find quite unacceptable. A lot of people may find it acceptable but a lot would find it totally unacceptable, and I personally find it morally repugnant.

Now Archbishop Doyle and his co-presenters the other day said that they thought any form of assisted dying lacked dignity, and we are saying that this form of assisted dying epitomises dignity and I think we just have to agree that we are going to disagree on that one.

The salient point to make is that, it is not up to what Archbishop Doyle thinks, and it is not up to what I think or anyone else thinks; it is up to what the patient thinks is for them a dignified death. It is up to them to decide what is intolerable. We cannot tell what they are suffering because we are not experiencing it; it is their suffering.

There is a comment made that because so few people would need to use this legislation that it is unsafe or not fitting to have legislation for all of the Tasmanian population that is only for a few extreme cases. I'd like to use the argument that, even though there might end up being very few users of this legislation, the fact that on all polling about 80 per cent of the population supports this sort of bill, suggests to me that the majority of people do see themselves as potential users of this legislation. No-one can know what the end of life has for them. A lot of people are very fearful of what might be and, even if it does not happen, the fact that they have to live with the uncertainty of not knowing what will happen to them can be a very big problem. A lot of people really need the reassurance that, should this sort of situation come to them, they will have in place a way of dealing with it. So, even though it might be used, as I say, by only a few, I think the fact that the majority want that reassurance - and this is shown by the number of people who go overseas to get their supply of Nembutal. They would not be doing that unless they were fearful of what the future might hold. As it has been pointed out in Oregon, even people who get medication to have as a security blanket, often do not end up using it; it is just the peace of mind knowing it is there if you do get to the stage where you have intolerable suffering.

The other thing that has been expressed too is that introducing a law like this would give suicide-prone people the notion that suicide is quite acceptable in the community. As I have pointed out, the way we envisage this happening is that it is done very privately, it is done between the people who know the patient; maybe their relatives, doctors concerned, the coroner learns about it; but it is not going to be published all over the newspapers. It is a very private matter in a private place and I doubt very much whether the general population would even know the event had occurred. So, I cannot see it having any adverse effect whatsoever on a general population who will probably not even be aware of the event.

Morality, compassion and individual free will or autonomy are the important crucial issues of this whole debate. We believe that the current law does not fully respect or reflect these values and, therefore, should be changed. Laws are not stable; they change with the changing views of the population. Sometimes they change very dramatically. For example, in Victoria where one day it was illegal to procure an abortion and the next day it was illegal not to provide an abortion to anyone who asked for it. That shows that the law can change very dramatically and that it is not sacrosanct. The Archbishop of Canterbury has said in this book here:

'The law must never inhibit conscience.'

I think there are many people today who adhere to this principle, and I think there are probably quite a few doctors who have allowed their conscience to take precedence over the a law which is changeable, but their consciences are probably not so.

Finally I would like to say this to the law-makers: when you are considering this legislation, please do not ignore the plight of the few with intolerable suffering. Please do not ignore the wishes of the majority who need certainty and reassurance about their own end of life matters, and please do not ignore the relatives and the doctors whose consciences are in conflict with the current law and who choose to follow the dictates of their conscience at the risk of paying a legal penalty.

CHAIR - Thanks, Dr Dunn.

Dr CUTTS - I was a general practitioner for most of my working life in Devonport, but I have been retired for 10 years. In the last 10 years of my practice I was very involved with planning, developing and running a special unit for dementia patients with difficult behaviours. In that last 10 years when palliative care became available and good, it was very gratifying to be able to look after people really well at home with the help of the palliative care nurses. I had many experiences where, for the people dying and their families, it was a wonderful growing experience, but there is this very small percentage of people who - even palliative care specialists agree - cannot be helped, and that is what this bill is all about. It is not about the disabled and the depressed, which is what a lot of people have been bringing up, but which I think is really quite irrelevant; it is about that very small percentage of people. Once someone is suffering to that extreme extent I cannot see how that can ever be a growing, positive experience for either the person or for their family, because they are in such tremendous suffering. How can they think about it being a positive experience or think positive things? Up until that time, yes, we can have a lot of wonderful communication between the family, as has been said today, but not in that last very intolerable suffering.

I made a submission of my own supporting the Dying With Dignity bill, but I would like to talk a little bit more about what seems to have been concerning a lot of people today; terminal sedation and what has been happening over the years. I think it is important to remember that a doctor's duty of care continues right up until death. I was really alarmed to hear this morning the idea that the gentleman in Western Australia should be discharged from his aged care facility because the nurses should not have to look after him if he decides that he is not going to have any more sustenance or liquids, and also the fact that the medical health system should not have anything to do with euthanasia and that we should have a death system instead. I found that really quite disturbing because our duty of care continues up until, and after, the person has died, and this means that everything should be done to make that dying process positive. It means that, in this very small minority of cases, we should have the possibility of someone choosing physician-assisted suicide. Doctors have always, since time immemorial, helped people to die, and up till now many doctors have helped people to die. Up until now, many doctors have given lethal injections to their patients. You are not a good doctor unless you do this at times, however difficult it is and however much you know that it's risky and you may come to grief with the Criminal Code. That's always been the case and it's always been a difficult thing.

In the last 15 years or more, we have had good palliative care, we have had syringe drivers, and it is regarded as best practice and a standard practice that we use what is now called 'terminal sedation'. It is used in palliative care all the time but the bad thing about terminal sedation is that there is this double intent. When you start terminal sedation and there has been quite a lot of discussion today and a bit of confusion over this - it is nearly always used with a syringe driver, which gives continuous delivery of the drug and it consists almost always of two drugs. One drug renders the person unconscious and the other drug is almost always morphine, to alleviate their pain. Really, when you start terminal sedation, if you are absolutely honest, that patient is not going to wake up again and it is only a matter of how quickly you administer and increase the dose of morphine as to how long it is going to take that patient to die. So it is a case of, 'Yes, we have hooked up terminal sedation to relieve their suffering but we actually know that we are going to hasten death', and a lot of doctors feel uncomfortable about this and delude themselves a little and do not say honestly to themselves that this is going to end up hastening the patient's death. I think because a lot of doctors are a bit uncomfortable about this they do not increase the morphine quickly enough and it often takes days and days before that patient dies. It is not distressing for the patient but it is often very distressing for the relatives.

I am probably talking from the general practitioner point of view perhaps more than from palliative care in hospitals, but a lot of doctors feel a bit uncomfortable and uneasy about this terminal sedation, because if you are absolutely honest with yourself - as Nick McKim was very straight-down-the-line about it today, talking about it being manslaughter - you could say that it is actually a sneaky mercy killing, which is what doctors have been doing forever, giving people a big dose of morphine. That really is mercy killing, but because a lot of doctors still feel uncomfortable about this, I think that inhibits them from really having good and open discussions with the patient about what they are doing.

One of the good things about a bill like this, if it becomes law, is that it is really going to increase the communication between doctors and their patients and the relatives. I did talk a lot to my patients - to the dying person and to their families - but I do not think that is always the case because doctors do feel uncomfortable. I know in the bill it does not say anything about how physician-assisted suicide should be undertaken but I do hope that a natural result of a physician-assisted suicide bill becoming law either here or in another Australian State, as is inevitable within the next few years, I think, will be that Nembutal will become once more available for use in physician-assisted suicide, because I think that is the holy grail and very much the choice that the majority of people would choose as their way to die. I feel strongly that this is the way to go, as it is in Oregon and Switzerland. It seems to me a much better way of doing things than what happens in the Netherlands. I hope that that will happen after we start getting bills such as this in the States of Australia so that we are able to offer this option to people.

- **Ms FORREST** I think you've probably heard me ask the question of the AMA about the complexities of a number of safeguards built into the bill. Do you really think it is going to work in a way that facilitates people who are in the situation you have described?
- **Dr DUNN** I think it is unwieldy but I think that is why bills are put forward, so that people can have input and make readjustments and simplifications. I think it is fine for people living in Hobart and perhaps in Launceston but I agree with you that people in country areas are going to have great difficulty.
- **Ms FORREST** So if it's to meet the needs of all Tasmanians who want access to it should reflect the whole State, not just sections of it. That is one of the tests that I, as a legislator, am charged with. How do you see that the bill would need to be amended or changed to enable that?
- **Dr CUTTS** I think one of the things that might be able to be discussed would be the need for having a psychiatrist. That will be one of the most difficult hurdles to get over. It isn't in other bills.
- Ms FORREST It was in the Northern Territory one.
- **Dr CUTTS** Yes. This bill has been created with a great many safeguards. It medicalises it a great deal and makes it difficult to get over all the hurdles. I think that is one of the safeguards which could be discussed and which perhaps is not absolutely necessary. In a lot of cases the doctor looking after that patient will be their GP who has probably known them for a long time and has possibly discussed end-of-life decisions over a long time with that person. A GP like that is probably very capable of knowing whether that person is depressed or are competent to make that decision.
- **Ms FORREST** Having made those comments, when you look at the requirements that are placed on the medical practitioner, nowhere in this bill does it say that the medical practitioner has to have known that person for a certain amount of time, to be aware of the medical condition, or to have had a long association with that patient. They may have treated them for depression in the past or have seen the progress of their illness. Is that an issue that needs to be tightened up? Further to that, do you think we should include something such as advance directives being an important step before any of this starts so that before people even have an illness that is classified as terminal -

- **Dr CUTTS** I can't stress strongly enough how important the enduring guardianship provision in Tasmania is and how it is possible for people to put really good instructions and wishes into the enduring guardianship. If it is not an advance directive as such but the great thing about it is that you are able to put anything you would put in an advance directive about your health into that enduring guardianship and once it has been registered it is a legal document. From that point of view we are very lucky -
- **Ms FORREST** Should that be included as a necessary step in the bill? Should there be a requirement that people have a registered enduring guardian, but obviously it may need to be reviewed over time. As you review that you still have that legal document that enables decisions to be made about your care at the end of life.
- **Dr CUTTS** That is ideal, but it may preclude certain people just because they haven't got one. That is the problem. There may be a few that don't, but I think almost all aged care facilities in this State are now encouraging and having people do an enduring guardian when they are admitted to that aged care facility.
- **Ms FORREST** There are certainly people that are suffering from the sort of illnesses we are talking about. We are not talking about sudden deaths. We are talking about long-term pain and suffering, and long-term can be anything from weeks to months to years. Generally unless that person has a pre-existing incapacity issue then they would be able to be advised to do an enduring guardian at that point, so I do not see a problem. I just want to ask why you think it should not be included here as a safeguard?
- **Dr CUTTS** Well, it could be difficult. You can put it in the bill, but I do not how you are going to put it in and word it that they have to have that, that they are compelled -
- **Ms FORREST** Well, they have to see a psychiatrist. They have to see two doctors. They have to be over 18. They have to jump through about 55 other hoops.
- **Dr CUTTS** Yes, but at what stage are you going to say that that enduring guardianship should have been done? Ideally it should have been done years ago, but certainly it should have been done probably before they have the diagnosis of that terminal illness, and that may not have happened.
- **Ms FORREST** Not necessarily, because there are people who are diagnosed with various forms of cancer, and that is a bit of a wake-up call for a lot of people, and some of these cancers are curable. Some of them are able to be put successfully into remission for many years. It is often at that point that those people then think, 'I need to make a decision about my end of life', so they go and do an enduring guardian at that point.
- Dr CUTTS Yes, they do.
- **Dr SING** I think everybody should have the enduring guardianship, but to add another hurdle that people have to have before they can access the bill would be most undesirable. If there has been consistent advice reflected in legal documents like the enduring guardianship and if it has been made absolutely clear by the individual, and I think there would be quite a lot of us here who have done that, then is it necessary for a

second doctor? Could that be sufficient evidence so that we could just reduce one of those major hurdles?

- Ms FORREST This is the reason I am asking how you think it could be amended if necessary.
- **Dr SING** If there has been consistent advice by the individual that in these circumstances this is what they want to happen, and it is reflected in a legal document like the enduring guardian, then the consulting doctor would only have to consult one other medical practitioner, whether that is a psychiatrist or another doctor. Where there is strong evidence of a consistent point of view by an individual then I think you could reduce one of the hurdles.
- **Ms FORREST** Should the requirement be that the patient is known by their doctor for a period of time?
- **Dr SING** Perhaps that is one of the things that could be part of it. Perhaps in that case you could reduce the thing, but it is quite difficult sometimes. I have been going to the same doctor for 25 years. She is about to retire, and I am going to have to go through the process of finding another doctor. I go to a practice and I often see doctors within that practice who do not know me very well. They have a lot of stuff from my history, but it is not always easy to stay with the one GP.
- **Mr GAFFNEY** And some doctors may not want to be involved with VAS, therefore there will be quite a few of them who would want to withdraw, so I don't think it would be possible to work that way.
- **Ms O'CONNOR** I put this question to Dr Dunn. We heard evidence today from the Australian Medical Association and they have taken a very strong professional philosophical position on voluntary euthanasia and clearly there are some doctors who feel very uncomfortable about what is being proposed here. How do you respond to that?
- **Dr DUNN** That is their position but equally there are a number of doctors who have the opposing view and who do support it. Not all doctors belong to the Australian Medical Association and not all doctors belong to these groups, and even if they do they still differ from the general line that is taken. My understanding is that the Australian Medical Association was fairly neutral anyway. I think they were very much opposed to it at one stage but I think they are becoming more neutral.
- **Ms O'CONNOR** With respect, it certainly did not come across that way today. There was a very strong position.

One of the other arguments that has been put, and in particular this comes from people who represent religious organisations and church leaders, is that, yes, the individual's desire for personal autonomy is a laudable personal ambition but that has to be balanced against the wider community's interests. If we are narrowly focusing on individuals who are suffering, we potentially put other people in the wider community at risk; we make them vulnerable. I throw that open if people have a response to that. It is the slipperyslope argument.

- **Dr SING** I believe that is a very paternalistic approach, given the safeguards here. It is an opinion about pressure about which I do not think there is any evidence. There is no evidence for it in the Netherlands. After 20 years experience there is no evidence for it in Oregon, yet people continue to say that other people are going to be pressured. If you think about the individual who is being pressured, first of all they have to have terminal illness. They have to have a level of suffering that three doctors have to attest to in different ways. Is there going to be anything in that process for the individual to say, 'Oh, my family really want me to do this'. I do not believe it is a realistic or reasonable thing to claim that so many other people are going to be at risk as a result of this. There is no evidence. It is an opinion that keeps being repeated as if it is fact. It is merely an opinion, an opinion that certainly the Dying with Dignity Tasmania people would say is not the right opinion.
- **Dr CUTTS** If a doctor is looking after this terminally ill person for weeks, months or however long, and if their communication with that person and the family is as it should be and is good, then surely that doctor will have some idea if there is any pressure whatsoever from the family wanting to get rid of the person or having any pecuniary interests. If there is anything like that going on then surely that caring doctor should have picked that up. I do not think there is any real risk of this.
- **Mrs BUTLER** As a trainee social worker I was given the task of telling someone that they were going to die. The referral came from a specialist who had been seeing the person for 26 years and felt that he was too close to the patient to tell him. Because the patient was in a morphine-induced state I was seen as an angel, which gave me a lovely way of working. I think this is a real stumbling block. We are talking about the need for the doctors to know them very well but you do have that other side of the same coin and they have become too familiar. I just wonder if we can tease out this process a bit more.
- Dr CUTTS Surely that should make it easier and better for both people the person and the doctor to have a meaningful conversation about the fact that they are dying. I find that very strange. I worked with a cancer specialist I will not say whether he was an oncologist or a radiotherapist, so nobody can identify him this is some years ago now, but he obviously found it so difficult to talk to the patients and tell them what was going on and what the prognosis was and the fact that they were terminal, that he just did not do it. The stress that went on I had several families that had to cope with this and I realised that the relatives had been told, but not very well, and the poor old dying person was never told.
- Ms FORREST How long ago are we talking about?
- **Dr CUTTS** This one was probably about 12 years ago. Not all that long ago; I hope it does not happen now. There are doctors who find it very difficult, but once you are able to have an open conversation, firstly with the person who is dying and then with the relatives who are so relieved and grateful that everybody knows and everybody can talk about it. The stress usually vanishes because they can then start to communicate. Sometimes that person had been advised that it is better not to tell them. It is not all that long ago, but there are people in the medical profession who find it very difficult to talk about it to the patient.

Mr HARRIS - In conclusion, I would like to thank the committee for hearing us today.

- **CHAIR** I would like to point out that, in respect of the evidence we have heard so far, this is not the end of it, we still have other witnesses to receive. Also, I would point out that there is sometimes an imbalance because of the availability of people and we have found that to be quite an issue. We have also had a couple of withdrawals today. So, we are at the behest of the people who wish to give evidence, who put in submissions, who are invited and who then choose to turn up. We are taking more evidence and looking to be as balanced in our evidence-taking as we possible can be.
- **Dr SING** I have the Doctors Reform Society policy on euthanasia which is significantly different and I can't speak for them but it may be of interest to you. As I said, we have made an analysis of some of the inaccuracies and so on and when the committee has had a look at it we will forward it to you, if it is of interest to you.

THE WITNESSES WITHDREW.

<u>Dr PAUL DUNNE</u> WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

- **CHAIR** (Mr Finch) Doctor, we very much appreciate your patience in allowing more time with our previous guests. Thank you very much for that. We are prepared to hear what you have to say and I realise you have put a submission to the committee, but we would like to turn over to you now for a presentation and then we will ask you some questions.
- **Dr DUNNE** Certainly. My submission is before you so some of what I might say is repeating what is in there. My background is a medical practitioner of almost 40 years now. I spent time as a general practitioner working at Bridgewater and I have also spent the last 18 years working in palliative care as a specialist in Tasmania. Until recently I was the only specialist on the island in palliative care. My position on the Dying with Dignity bill is that I oppose it. I have a number of reasons for that, some of which are personal which I will share with you in due course, and some of which I believe relate to the process of the community, society and the medical profession per se.

The bill is drafted with a lot of safeguards and, as such, I believe they have made the bill unworkable because they present a lot of hurdles to people who are coming to the end of their lives. I also think that, in some ways, the process of the bill is at a stage where it conflates a problem which may not exist. My feeling is that there may be a small number of people for whom end-of-life care may be difficult to achieve comfort. Good palliative care, attention to detail, and attention to the needs of the family are very important. My medical position is that it is not my purview to be involved in the deliberate ending of someone's life to a timetable that is inside my control.

One of the concerns I have is that the profession is still evolving its attitude towards death and dying. We know that people have been dying for millennia. We know that people usually die quite happily and well often without doctor input. Most recently I suspect that a lot of medical input may have been to totally confuse and conflate the problem of dying and to add burden to people who are coming to the end of life.

In part of my submission I talk about the change that has occurred in the last 50 years around death and dying. Fifty years ago, before the advent of penicillin, before the advent of a lot of cancer therapy, death was, essentially, a quick process. You got sick, you had your infection and acute illness and mostly died very quickly in that way. These days there is a process where death can be delayed for long periods of time and the medical profession has become very adept at prolonging life often with good events, but sometimes with the process of just adding a burden to other people.

Part of what we need to do in a community is begin a discussion around death and dying and how it should happen in the community. I think if the first decision-making process is that we can now kill people as part of an end stage of the discussion, it stops any of the other discussion from occurring and from happening in a logical way. Doctors are not trained to deal with the dying. They are not trained to talk with people to any extent; they do have communication courses now, which has been part of medical training in the last 10 years, but any doctor who has been practising for more than 10 years was never taught to communicate, was never taught about people's feelings, was never taught how to talk with people who may be dying. The idea of saying, 'Okay, I do not have to talk

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with you now but you can have euthanasia', strikes me with fear in terms of how a medical profession can side-step this responsibility to talk with people appropriately and work out how people can live and how people can die in an appropriate way. I do not think the medical profession has a remit to actually be the agents of death. It is not my training, it is not my idea of what doctors should have been taught to do or should actually do.

I think there is a misconception in the community that all doctors know about death and dying. I think there is a problem associated with doctors' familiarity with people at the end of life.

Various studies have been done with show that, in any one year, a general practitioner may take care of about six or seven people who are approaching the end of life from an anticipated illness. A physician may deal with 30 or 40. A surgeon may deal with only a few even though they are dealing with people who have serious illnesses. Most surgeons, once their operative phase has finished, hand across to general practitioners and physicians in that way. So the ability of people to learn the skills to talk with the dying is actually fairly limited. It is not a subject that people often talk readily about in terms of what are your issues, what do you want and how do you want to manage your end-of-life processes? To this extent I suspect a lot of people end up on a treadmill of treatment rather than a treadmill of the most sensible thing to do in this arrangement of your illness.

People do not talk about what will happen when they get a severe infection. People do not talk about, 'If I go into hospital and I am severely ill then I do not want to be subject to cardio-pulmonary resuscitation'. We know full well that the chances of living meaningfully after leaving hospital after a cardiac arrest, where your heart stops and you die, in a general medical ward is less than 10 per cent. It is not as good as *ER* or any of the other television shows would have you believe. You have problems as you get older. As you have more illness, more co-morbidities, your chances of dying from a hospital admission are actually higher, yet your ability to say to people, 'No, I do not want that', is hampered by people's inability to have conversations and to discuss realistically what the goals would be. Putting in place a process which overcomes a number of steps without really giving a chance for communication to occur, strikes me as being inherently wrong.

- **Ms FORREST** On one of your last points about discussion about death, we have almost, as a medical profession, lost the ability the let people die even when they are trying to really hard sometimes; we keep stopping them or trying to stop them. With the work of Elizabeth Kubler-Ross I am not sure how many years ago that was -
- Dr DUNNE It was 1969.
- Ms FORREST She did a lot around talking about death and the grieving process around that. Are we now at a point where we need to have another discussion about dying, like with premature babies and older people? I am not sure what 'old' is these days but whatever it is -

CHAIR - It is much older than me.

Laughter.

Ms FORREST - It is always older than oneself, obviously.

Dr DUNNE - Yes, we do.

- Ms FORREST How do we facilitate it?
- Mr WHITELEY How do we do that?
- Dr DUNNE I do not know the answer as to how one can do it, other than to put it out there for comment. The speakers before were talking about advanced directives. There certainly is a need to consider what people think about at the end of life in terms of advanced directives. People need to be re-educated about the limits of medicine, what medicine can do and what medicine can't do. If you do have an illness which has a trajectory towards death, then that is the beginning of the discussion in that way. There needs to be a certain degree of discussion within schools about death. Death may happen to individuals and individuals will die across the spectrum. Death awareness is something that is not really part of our society to any extent anymore. Yesterday I had a conversation with a family whose mother was dying. She was in her late 80s, and the family hadn't any previous experience of anyone dying in the family, so her 50-year-old children haven't had anyone else that they know of in their immediate family who has died. When I was a kid one of the things we used to do every Friday was get out on the main street in Brisbane to form an honour guard for everybody who had died that week before. As the funeral corteges went past we'd doff our hats, and death was part of our lives as part of that process. Now death is something that happens to someone else, somewhere else; is not something that is always in our face. When it comes to us it is always new. We do not have that familiarity with death in our society: what do we do, how do we cope with it, is it abnormal, do we need to sanitise it, do we need to make it all nice and neat, do we need to kill this person so they can get out of our way so we can get on with our lives and not have to worry about it anymore?
- **Ms FORREST** Medicalising death to the extent that we are medicalising birth, is that the issue here? Do we need to wind back the clock?
- **Dr DUNNE** I do not think we need to wind back the clock. How do we get a conversation in our community which has realistic limits attached to it. We die from life. We do not die from an illness. We die from the end of life. It is part of that process that is going to happen to us all. In schools there are some children who die, but more importantly in schools you have a whole range of grandparents who die. There is very little in the way of death education in schools of how you cope with the grandparent dying, yet every year in any classroom there is a grandparent dying. It is a major tragedy that is not handled all that well. It should be normal. It should be something that says, 'Okay, we are looking at death and bereavement in primary school'. We need educational people to help with that, but it is a process of saying that this is a normal event. How do we get our community to talk about death and dying properly? How do we organise that process of having a medical community that does not practice all-or-nothing medicine, that does realistic stuff? You have the conversations with people. You say what the limits of care are. You limit the processes of saying, 'We can't cure you. This is an illness we can't cure'. We need to say that and we need to reinforce that process to people and work out how we can treat them to the best of our ability without prolonging

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their living to an extent where it becomes a burden and without hastening their death to the extent that it is obscene.

- Ms O'CONNOR Dr Dunne, are you a religious man? Does your position on this issue come in part from your faith?
- **Dr DUNNE** No. I was brought up a Catholic. I was in a way thrown out of the Catholic Church when I argued with the Bishop of Brisbane about divorce. I got involved with the Anglican Church and I was there last Easter. I have become a good Anglican but, no, my background is not from a religious perspective. I feel from the perspective of families needing to make sense of someone's life. You would recall a newspaper article which featured me at one stage and which has attracted a number of issues and comments about growth and all those sorts of things. One of the interesting things that does occur with someone who is dying is often the gathering around of family. That time for that family is often very important. Every family member has a slightly different understanding and aspect of the person in the bed. It is like seven blind men and an elephant; they all have a different sort of picture of that person, and it is only sometimes on the death bed when the family puts together a whole picture of that person rather than the individual they knew as their dad with six other brothers or three other sisters or whatever that they can then see the totality of that person in front of them. That can be very valuable and what I meant by a growth experience for the family in that way.

Decisions to end life are often made privately and everybody will say, 'Yes, I respect your decision to go along with that, dad or mum', but they may not have the ability to sit around and discuss it and do some of the preparatory work for allowing people to die, which is sometimes taken from them by the suddenness in that way. Sudden death does occur, I cannot prevent that from happening, but it is that process of finding meaning in terms of end-of-life care that is important, and often the person in the bed has a pivotal part to play in that process as well.

- Ms O'CONNOR Well, they're the sufferer, and I guess that's where my next question goes to -
- Dr DUNNE Sometimes they're not the sufferer; sometimes the suffering is transferred.
- **Ms O'CONNOR** Sure. We were presented earlier today with a brief paper to the Archbishop of Tasmania from Barbara Glidewell MBS, Hospital Ombudsman, Director Department of Patient Relations, senior scholar at the Centre for Ethics in Health Care in Oregon Clinical Palliative Care, Clinical Pastoral Care. I just want your response to one paragraph of this because it is looking at things from the sufferer's perspective. Barbara Glidewell has been intimately involved with the Oregon laws for 11 years and she is the doctor who conducts the interviews with the person who is making the request, and she says with respect to the Archbishop:

'On this issue, those who are care-givers or observers often say, "Well, just lie back and wait for death to come. We'll take care of you." This is easy to say when you are not in the patient's situation. One cannot know the terror and fear of the exacerbation of symptoms patients know are oncoming and the disastrous effect on their psyche as they endure for others - that is, "Oh Mum, I just can't stand to lose you. Please hang on." Family members need to realise we all face our death at some time. They must compassionately give their loved one permission to let go so that the loved one can gently and sweetly let go.'

What is your response to that?

- **Dr DUNNE** I think that comes back to that process of having an educated society that knows about death and understands the discussion around that. There is an issue where we have a concern that people who are coming to the end of life will suffer. Part of palliative care is to work with patients and their families to prevent suffering from occurring. We can't do it; it's not possible. I can't prevent people from suffering, because suffering is a human condition that is with us, no matter what. I can prevent people's pain, I can prevent their breathlessness, I can treat their symptoms really well, I can provide a level of support and possibly within the widest breadth of the term 'pastoral care' to people to make it normal. If the doctors don't run away from the face of death, I can make death normal, in a sense. To see patients in their beds who are lying very comfortably and to see families around talking about the person in the bed as suffering makes me wonder who is doing the suffering here. I agree that there are sometimes issues in terms of unresolved pain.
- Ms O'CONNOR And that is what this bill seeks to address, isn't it?
- **Dr DUNNE** Yes, but unresolved pain is relatively rare. We have taken our figures in our unit and in effect I see about 350 patients a year, so 18 years gives me a fair patient base, and over the past 18 years in the unit we have had 17 people in whom a clear decision on palliative sedation at the end of life has been made, which is not a large percentage in that group. The majority of that has been for unresolved pain and where the process of remitting that pain means that we need to get rid of the person's awareness of the pain; in other words, we make them sleep.
- Ms O'CONNOR Is that not an act of euthanasia?
- **Dr DUNNE** It is an act of good medical care, I believe. We don't draw up the 'green dream' and put it in their vein and say, 'This ends now'. We make people sleep. There are situations where people will fade into sleep over a few days where they can say, 'No, I don't like this'. We have had a couple of people who have woken up after 48 hours and said, 'That was good. What do we do now?' That means I am not terribly good at giving people maximum sedation but sometimes you can make people a lot more comfortable when you take away some of their sensorium for a while.

Some of what we do in palliative care will hasten death; that is a given. Some of what we do in palliative care will prolong life; that is also a given. If someone is in severe pain, the pain will kill them quicker than anything else will, but we can relieve that pain and allow them to live a lot longer. What we try to do is neutral, to a large extent. I know that if I admit someone to the ward and they are in excruciating pain, I need to give them medication to get them out of pain. If I pursue that to the point of their unconsciousness I see that as part of my role of being a good doctor. I then do not have to put up a drip - put in a peg tube - to feed them and put them on a ventilator to keep them alive until such time as they die. I think that is silly, but I do not think I need to

actually intervene at an immediate point in time to say, 'Your heart ends now'. It might take two or three days or a fortnight to die but that's the way life is.

Mr GAFFNEY - Thanks very much. An earlier speaker today highlighted the issue that you touched on about people being unaware and not wanting to communicate. In Oregon, when this decision came about they found that the government actually put a lot more resources into palliative care and awareness education to make the community more aware. That would allow the individual to choose to end his or her life without legally harming the persons that they may need to assist them. So my question is: now that the medical profession is so good at prolonging life and taking care of people, perhaps the next step is to allow the final days of somebody's life to be done in a - I am not sure if 'dignified' is the right word - manner that they choose, so that if they want to exit this world it can be in a lucid state with their family and friends around them.

They know that the end is maybe two or three weeks away if they can be kept on for that long, but maybe they would prefer just to say, 'I know in three weeks I am going to be dead. I am going to go through a lot of pain and anguish and so is my family. I choose to end my life now and I want to do that so that the physician who I have a lot of time and respect for is not going to get into trouble'. Some part of me says that that is quite a reasonable and mature way of a community looking at this. Instead of some of the scenes that we have heard about here where a person had to starve themselves to death because there was no other way for them to do it without somebody getting into trouble. If somebody comes at you with that sort of approach, how do you respond to that?

Dr DUNNE - The argument has always been around what is proportional to providing care. Proportional medicine involves a process of providing care for the person with the symptoms that are in front of them and you look at how they are going and implement or decrement treatment as appropriate. The practice of medicine and pain control is one of looking at providing medication, reviewing how that is going and doing proportional response to people's comfort and pain. I see somehow or other, that the process of discussion around the parameters of care needs to be taken back a bit from the parameters of dying. It is hard to enunciate a process, but from a personal viewpoint - and one of the things that one always has to work through is that you can see the great logic in that - I can understand how people can be in that position. I do understand that it is obviously an argument where palliative care and euthanasia, dignity of end-of-life - the arguments are basically the same; we are talking about ensuring that people have a good and gentle exit. The process of how one does that is always the degree to which the profession and society can change.

The process of legalising the killing of an individual makes it a step-too-far, in my belief. I think that having the discussion around how we can ensure that people get good care, good treatment, is the way to go. There is a process of saying, 'Look, you are approaching the end of life. We do not need to be looking at how we actually give you more chemotherapy, more radiotherapy, to try to prolong your life. We treat the symptoms that are there and we make you comfortable as part of that.'

Some of medical dying can actually increase people's burden of dying. How you actually begin the discussion to reduce some of the burden that people have through their

treatments is also a discussion that needs to be had. I am not too sure of the answer to your question totally.

- **Ms O'CONNOR** Dr Dunne, I am sorry, I do not mean to be rude, we are running a little bit over time so I have to dash off, but thank you so much.
- **CHAIR** Just a hypothetical question to conclude, Doctor. If this bill becomes law how do you think the relationship between doctors and other health professionals and patients will be affected?
- **Dr DUNNE** My conjecture is that it is going to be harmed. I suspect that there will be a number of people for whom the passage of the legislation will be greeted with hurrahs and hallelujahs and there will be a number of people in the community who will be very fearful of going to the doctor because of what the doctor can do. My major concern is what the profession can do and my personal concern is: do I know my own boundaries? I remember vividly a *Punch* cartoon in about 1977 of a Harley Street specialist treating a person who was earringed, tattooed, and with a mohawk, saying, 'That is a very nasty splinter. Have you considered euthanasia?'

It makes the practice of medicine easy if you have an end point that you say, 'Okay, we can treat you up to here and then we will give you the big pills'. It stops the communication. It actually allows the doctor to say, 'Good, I do not have to have that conversation because you have decided to do something else'. Can we stop pressure on individuals from occurring? No. The fact that you open up a law that says you can have euthanasia means that there is a subtle pressure immediately on people to say, 'They have legalised it, so I should have it not to be a burden to my family'. There are unspoken rivulets underneath that.

- CHAIR Is there anything you would like to say in conclusion?
- **Dr DUNNE** No, other than to thank you for having me this afternoon.
- CHAIR Thank you for your time.

THE WITNESS WITHDREW.