**THE JOINT STANDING COMMITTEE ON COMMUNITY DEVELOPMENT MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART, ON MONDAY 31 AUGUST 2009**

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**Ms LYNSEY SPAULDING**, CHAIR, NEURO MUSCULAR ALLIANCE TASMANIA AND **Ms HEATHER FRANCIS**, CHIEF EXECUTIVE OFFICER, MULTIPLE SCLEROSIS SOCIETY OF TASMANIA, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED

**CHAIR** (Mr Finch) - Good morning Lynsey and Heather, thanks very much for your attendance. We have 30 minutes allocated for you and my intention is to hand the floor over to you to make your presentations to us. I am assuming that you are going to present as well, Heather?

**Ms FRANCIS** - Yes, but I will allow Lynsey to commence first.

**CHAIR** - If you make your presentation we will ask questions at the conclusion. I intend to allocate 30 minutes.

**Ms SPAULDING** - I am representing the Neuro Muscular Association of Tasmania which represents seven neuromuscular organisations in Tasmania. They are the MS Society, Alzheimer's Australia Tasmania, Huntington's Disease Association, Motor Neuron Disease Association of Tasmania, the Muscular Dystrophy Association of Tasmania, Parkinson's Tasmania and the Spina Bifida Association of Tasmania. The organisation does not have a formal position on the issue of voluntary euthanasia; however, our view is that it certainly should be an issue for individual choice and obviously the current legislation does not allow for individual choice.

Our organisation's roles are to support people with severe neurological and neuromuscular disorders through difficult times including having a severe disease that might be a life-limiting issue and obviously we believe that dying should be as comfortable and with as much dignity as possible. Certainly not all of our clients that we represent have to face the issue that perhaps their illness is life-limiting, but certainly for people who are affected severely we believe that they should have the choice to make their own decisions.

Heather is here to represent the Multiple Sclerosis Society of Tasmania.

**CHAIR** - Is that what you would like to present first up?

**Ms SPAULDING** - Yes.

**CHAIR** - We will let Heather make her presentation then.

**Ms FRANCIS** - Lynsey is a member of the MS Society's client services team so she has, if you like, a dual role here. She is one of our case managers for the MS Society and a valued member of our organisation supporting our in excess of 650 clients across Tasmania, so Lynsey has strong insight into the challenges of people as their MS condition progresses.  In recognition of her skills and expertise, she has been provided with the opportunity to represent MS as well, again verifying that Lynsey has a joint role.

The MS Society of Tasmania is an individual organisation but we also form part of an organisation known as MS Australia representing in excess of 20 000 people nationwide who have a diagnosis of MS.  As I mentioned, the numbers in Tasmania are in the order of 650 people registered with our society, however we do know that there are a number of other people with a diagnosis of MS who have not chosen to register with us.  We recognise that Tasmania has the highest prevalence of MS of any State in Australia and that people have differing experiences of this particular condition.  For example, many experience relapsing remitting MS where their symptoms may come and go over time and they may reach some degree of significance but then go into relapse, but others may have an initial diagnosis or may subsequently be diagnosed with progressive MS, and that is where disability and ultimately more palliative care may be the consequence.

We had a board meeting on Thursday night where I indicated that the opportunity had been provided to present to the committee this morning and the board asked me to reiterate their view that it is the individual's choice, so this is consistent with the view that is presented by NMAT that the society itself does not have a position upon the legislation, it is neither for nor against it, and I would add that that is similar to the view of MS Australia, there is not a formal position on legislation for dying with dignity.  Having said that, I think implicit in that statement is a recognition that under the current legislation there is no facility for the individual to make a choice to die with dignity.

That probably summarises the position of the MS Society; it is neither for nor against this issue.  It recognises that there are many people who will ultimately reach the final stages of this condition, which has no cure, and have a need for further care when ordinary palliative measures do not provide them with the comfort and dignity they require.

**CHAIR** - A question to you, Lynsey.  There are 650 with MS, so in the other organisations that you represent how many clients would you be dealing with under that umbrella?

**Ms SPAULDING** - It varies amongst the organisations.  I'd be hazarding a guess as to how many, but overall it would be around 2 000 people statewide.

**CHAIR** - Do these people share a similar deterioration in their condition in comparison with the multiple sclerosis people?

**Ms SPAULDING** - Some of them do.  Certainly motor neurone disease and Huntington's are almost always fatal, so the issue may be almost even more pertinent to those diseases. The disorders and diseases will differ in their rates of progression.  MS is a very individual disease and it is very difficult to predict the disease course and what will happen.  The other diseases represented by NMAT do have similar issues of progression, as such.

**CHAIR** - Is euthanasia a topic of discussion amongst these organisations generally?  Have you embraced the issue, other than dealing with the Dying with Dignity Bill?

**Ms SPAULDING** - We haven't addressed that as an organisation as such yet, but most organisations within NMAT have discussed it at their own organisational level.  Not until we were asked to represent NMAT in these discussions had we discussed it as a group. I think that reflects the fact that, thankfully, not all of our clients throughout NMAT are affected by the issue of voluntary euthanasia, but it is certainly an issue for a number of people.

**Ms FORREST** - Lynsey, you represent Alzheimer's Australia and Australian Huntington's Disease Association, two conditions that will result in death. With the way the bill is written, those people will be excluded because they won't be mentally competent to make such an assessment and then follow the very convoluted course of the bill. Do you see that as an issue?

**Ms SPAULDING** - Only if it hasn't been discussed, perhaps. If someone has put into place advanced-care planning and discussed with their family what their wishes are and perhaps appointed an enduring guardian to enact their wishes should they become no longer competent to make their own decisions around their health and lifestyle choices, I don't know whether or not the bill would have the capacity to factor in people who had had those discussions. If certain events took place with their health and they were no longer competent to make their own decisions, if they'd expressed those wishes and documented them formally prior to becoming not competent to make their own decisions -

**Ms FORREST** - The bill, as it stands, wouldn't allow that.

**Ms FRANCIS** - No. This was something that I, at a personal level, realised. Similarly, with MS. It can often be not only physical disability with the disease progression but also a cognitive disability as well. The requirement to complete the certificate within a certain time frame that is very near to the time of ultimate assistance would, I imagine, present some problems for individuals. That was a feature that I recognised as being problematic, that somebody's condition at a cognitive level might deteriorate. So while there is capacity to gain assistance with a signature, or the fact that they can't physically sign, it makes no allowance for any predetermination and the subsequent action once somebody may perhaps reach a certain degree of cognitive disability.

**Ms FORREST** - Surveys are interesting tools in that they can often give you what information you're looking for. There have been surveys done consistently showing between 70-80 per cent or more support for voluntary euthanasia. However, in countries where it is legal, it seems to be a very small percentage - even up to only 1 per cent - of people who go down that path and then avail themselves of it. In this situation, with the bill that we are looking at, it would seem that it would be even less because all the people who may want to avail themselves of that opportunity would be excluded. Do you think it is wise to bring in a bill that merely caters to a tiny percentage when we perhaps could look at other measures? Alongside of that, are there other measures that you think could relieve the suffering of the people you represent?

**Ms SPAULDING** - Obviously there are so many variables that need to be catered for, including someone's cognitive capacity to make those decisions and whether they are able to record those prior to the time where the issue of voluntary euthanasia is something that becomes and issue for them. Certainly the legislation would need to make allowances for those variables, which is a difficult one.

**Ms FRANCIS** - Again, this is possibly more of a personal reflection, but with an understanding of the client group that I represent. Understanding that dying with dignity has been a philosophical concept debated across the community for some time, there may be a sense that this is a step-wise or evolutionary process where the mechanism is put in place for those at a certain level of physical disability to make that choice. It was interesting to see the mechanism for monitoring uptake of this capacity, and then the chance to review that over time and consider whether perhaps the legislation might need amendment in order to respond to other needs. So one might regard this as a first step that is perhaps slightly less controversial. It does not accommodate cognitive dysfunction and then, in time, look at whether or not the statistic would indicate that it is not really meeting the need and whether it might subsequently be amended.

**Ms FORREST** - I accept your comments but there would be people who would suggest that it is the start of slippery slope. The whole slippery-slope argument is put about by religious groups and others, and it is one of their common arguments. Does that present any challenges in your mind? I know you are representing an organisation here, but is that an issue of concern, that once you start amending a bill such as this to take in other groups, then are you saying that if someone who has MS later in their life who may not be able to participate in society to the degree that we, who are sitting around the table, are now, does that mean that another person like Stephen Hawking is not contributing either?

**Ms FRANCIS** - Again, it comes down the kernel that has proven to be contentious all the way through this discussion and I do not necessarily believe that there is an easy answer for it. Perhaps at a community level - this a personal opinion - there is a need for legislation to allow for this. Perhaps the current legislation as it stands provides a clearer opportunity to start down that path, whether it is regarded as a slippery-slope, and for it to be reviewed in accordance with the community's perceptions on implementation.

**Ms FORREST** - Do you have any idea of the views of the people who suffer these illnesses?

**Ms SPAULDING** - Speaking anecdotally in regard to clients of the MS Society, rates of depression are 10 times higher than that of general population. Having the facility to make a choice about end-of-life decisions and voluntary euthanasia, if that is something someone wants to make a decision about, may allow some individuals more of a sense of control about their lives, which is something they do not have with a progressive illness which is very unpredictable. In our everyday practice with our clients, it is something that is expressed, that it is a valid choice. Ending one's life may be a valid choice. It may be something that they never choose to do because legislation does not allow for that currently. Having that choice available can sometimes be enough for some people, to know it is there and having more of a sense of control over the decisions.

**Ms FORREST** - With the higher rate of depression, does that put them more at risk of making decisions because they are depressed?

**Ms SPAULDING** - Certainly and that needs to be assessed and managed in terms of whether or not it can be treated medically or in conjunction with counselling. Certainly it does need to be assessed and treated.

**Mrs BUTLER** - Lynsey, I am particularly interested in the bill where it talks about 'terminal illness'. I wonder how your clients perceive their illnesses and what your interpretation is of that? Do we need to alter that phrase?

**Ms SPAULDING** - It is interesting because Huntington's disease and motor neurone disease are almost always fatal diseases. People with MS will generally live 95 per cent of the normal life span, but there is a percentage of people who ultimately die younger because of complications due to severe disease with their MS. It is certainly not considered to be a terminal disease at all, but some people's lives are cut short because of complications to do with the disease, so perhaps the term 'terminal' does not apply to many of the diseases that NMAT represent so that phrase may need to be reconsidered.

**Mr GAFFNEY** - Is it possible to get a breakdown of the people registered in the six or seven different organisations you represent?

**Ms SPAULDING** - Absolutely.

**Mr GAFFNEY** - On the question about intolerable suffering, one measure is pain and how to assess that. I am interested to know in which of the diseases patients will experience intolerable pain and in which they may never have pain, but experience lack of self-worth or whatever to make -

**Ms SPAULDING** - Suffering.

**Mr GAFFNEY** - Yes. So when you provide us with the numbers could you do a breakdown of each of the seven organisations because I would be interested to hear how each of those groups view this topic.

The slippery slope comes up quite often and I am pleased you referred to that. Some people see it as a slippery slope, some people see it as a controlled measure. You have obviously come across that argument before, how do you see with your clients it being a controlled capacity to make some decisions?

**Ms FRANCIS -** I think it does provide the opportunity for the reality of that choice to be introduced to a segment of our client group and for their response to be measured and the appropriate amendment to be considered in future if it is recognised that there needs to be further accommodation of those with cognitive disabilities.

**Mr GAFFNEY** - So if this bill is passed it would be well within your organisation's framework or benefit to look further into it?

**Ms FRANCIS -** Yes.

**Mr GAFFNEY** - There is a stage one?

**Ms FRANCIS -** Yes, absolutely. In fact it has been interesting to hear your comments. Lynsey was given the opportunity to prepare for presentation only towards the end of last week, but she did seek that opportunity to connect with each of the members of NMAT and it has been really interesting to view their responses. All feel extremely positive about having the opportunity to provide input into this committee.

The other element that I would highlight is that the various organisations, including the MS Society, have not had the capacity to be particularly proactive in the recent past in determining the needs and requirements of their clients. We have only within the last few weeks received funding through the charitable organisations grants program to undertake a significant census - rather than a survey - of our respective populations. We are gaining professional support from specialists in this area to undertake this exercise in the early months of next year. It occurs to me that, for the MS Society as the lead organisation conducting this project, it presents an opportunity to gauge the perceptions of the clients across each of those seven organisations.

**Mr GAFFNEY** - I noticed you said you are under the banner of MS Australia, is this a census across Australia or just Tasmania?

**Ms FRANCIS -** No, Tasmania only and it is being undertaken as an initiative NMAT with the MS Society as the lead organisation; recognising our client group is the largest and that we are the organisation that is best resourced to undertake this.

**Mr GAFFNEY** - Psychiatric evaluation is part of the Dying with Dignity Bill - you mentioned depression - and we have had some submissions or points of view saying that it overstates the need for that. How would you believe, within your client base, if it goes there, that that person is available or is necessary?

**Ms SPAULDING** - It think it is probably a good safeguard to ensure that people have the capacity to make those decisions, given that a number of neuromuscular diseases, including MS, entail cognitive impairment. It will ensure that someone has the capacity to make those decisions and understands the consequences of those decisions, including the effects on family members and anyone else who is affected by the disease. It will also assess for depression, but depression may be a result of feelings of helplessness and hopelessness about their situation, so perhaps depression may not be clinically a result of the disease process, but a result of circumstances. Having the choice about end-of-life decisions and having more of a sense of control if things did become unbearable may be directly related to that form of depression. I think having a psychiatric assessment it is important.

**Ms FRANCIS** - Interestingly, this was an issue that was brought-up when we had our board meeting. A number of members asked a little more about the nature of the proposed bill. Some had not had the chance to sit down and read it, and the issue of involvement of a psychiatrist was one issue that was raised. There seemed to be a sentiment that this was a positive feature of the proposed bill. We have a member of our board who is a GP and his views were positive with regard to involvement from that specialised field.

**Mr GAFFNEY** - This is my last question. We sometimes read that people in the Netherlands say it has opened the door a little bit for judgments about different categories of people from birth or whatever, and some issues to do with whether there is still a quality of the individual life, but if they choose to take their life what message does that send our younger people who may be in a similar living situation? Could you comment on the impact that that might have?

**Ms SPAULDING** - I think it would certainly depend on the individual because for most diseases it is very individual. The extent of physical disability and perhaps cognitive disability will certainly vary across individuals. You would hope that it would be more of an individual's choice and that their decision to voluntarily end their life would be in relation to their own individual situation, which has its own unique aspect. It would not necessarily be the same as someone else who has a similar level of physical disability, for example, but who has a great quality of life. It really does depend on how that is assessed and how someone views that and what their individual circumstances are.

**Ms FRANCIS -** Whilst knowing our own State society's attitude, we have no formal position on this and when seeking to ascertain if MS Australia has a formal position on this we were intrigued to see that they do not. I guess, if you like, reading between the lines, one of the four messages that as a Society we are very eager to convey, particularly to those who are newly diagnosed, is that MS, in itself, is not a terminal condition. We are quite open about acknowledging that in its progressive form there may be complications of MS that may ultimately lead to death. I think for us to project that it is a terminal condition, and that we should therefore have stance on voluntary euthanasia, would send a message that is in conflict with that stance.

**Ms FORREST** - Just following on from what Michael was asking; do you think the membership - and I know they probably have not had a lot of time to think about it - appreciates the issue as being one of a doctor administering a drug that is effectively intended to kill a person? Do you think there is a misunderstanding that we are not talking about withdrawal of treatment or not commencing treatment - particularly with MS when you get some complications such as pneumonia or whatever which, if untreated, could be the complication that ends up killing a person? Again, this comes back to part of the enduring guardianship argument. Do you think that it has all been lumped in together - that withdrawal of treatment, not commencing treatment when it is against the person wishes, or not commencing futile treatment is all wrapped up?

**Ms FRANCIS -** I think it is. I think that some people haven't necessarily separated the issues of withdrawal of treatment or non-treatment from assisted suicide.

**Ms FORREST** - I know you probably can't answer this either but I just want to get an idea whether from the survey you're doing here that difference can be clearly identified. When people ring up doing their telephone questionnaires asking if you support this or not support that, unless that sort of thing is clearly articulated people tend to think, 'I want to have that right at the end of my life, I want to make choices', and I think all of us individually do. But do we really know that there are other things in the mix here? Would it be a fair comment to suggest that people probably are lumping it together when there is this broad support; that they are supporting that aspect as well as, potentially, the voluntary euthanasia debate?

**Ms FRANCIS -** Yes, definitely. I believe that there is a tendency for people not to think too deeply about the various options that may be made available and so in making a decision it might be more of a global decision rather than any more considered thought of the various options of passage. I have to say I am extremely reticent about using our survey instrument as a tool to gauge the perceptions of our clients because, again, it is suggesting that we should have a stance on this and I do not necessarily believe that we should. I think it may also present debate on the issue of whether or not MS is in itself terminal in the message that we are sending to our new clients.

Perhaps as community debate at a broader level continues there might be an opportunity for us to gauge across our various clients their points of view. I do not necessarily think that this particular survey, because it is the first for some time to gauge needs, might be the opportunity to do that, but I think in time and as community debate continues, there may be some scope for more considered discussion of this, perhaps not so much through the survey but more through something like a focus group where we can go into these issues more deeply.

**Ms FORREST** - Do you think that there is a fairly good understanding amongst your clients of the palliative care options available to them or is that a bit of a lacking area as well?

**Ms SPAULDING** - I think perhaps not, probably not. As Heather was saying, we try not to convey that it may need to be an option for our new clients. That is something that is addressed at the time but people are aware of the respecting patient choices initiative. I think people to some extent are aware of the options available to them but certainly may not relate that to their own experience with the disease.

**CHAIR** - Lynsey, are living wills and advance directives part of your counselling and discussion that you have with your clients?

**Ms SPAULDING** - Absolutely.

**CHAIR** - To what extent?

**Ms SPAULDING** - Obviously it is on an individual basis. Our client services manager undertook some training a couple of years ago in advance directives and coaching people through that process and how to document them and how to express clearly and discuss it with your family and the implications that they have. Certainly we do provide information to our clients about enduring guardianship and enduring powers of attorney just in case, or if it is an issue that might present for someone down the track then it is certainly information that we may broach with our clients very sensitively. But we do promote the fact that we have information about being prepared. We certainly say to people that it is something that everybody should do, whether they have a chronic illness or progressive illness or not, to actually articulate their wishes and discuss that with their families in case anything happened but it is perhaps more pertinent to someone who has an aggressive form of progressive neurological or muscular disease.

**Mr GAFFNEY** - Enduring guardianship is interesting and has come across the table before. When you mention that to clients and families, has it come across as a bit of a surprise to some of them that that facility or capacity exists? The lack of knowledge within the wider community about that has certainly been brought up at this table before. Is that what you have found?

**Ms SPAULDING** - Some people are aware of it and some aren't. I think the Guardianship Board has done a lot to promote it and their web site is excellent for accessing various forms and being able to download them and read the information attached to them, but I can't say that most people have been surprised or unaware of the capacity to appoint an enduring guardian.  Perhaps they weren't aware of the processes or hadn't thought about it, but most people, in my experience anyway, were aware of the capacity to do that.

**Ms FRANCIS** - I think it comes down to that distinction between awareness and understanding.  Whilst there may be an awareness, the depth of understanding is often not there, but we see that as part of our role to support them.

**Ms O'CONNOR** - I understand that the MS Society doesn't have a stated position on voluntary euthanasia, but I am wondering if you can see how, for many of the people that you represent who are slowly losing control over their physical being, it would be a matter of personal autonomy.

**Ms FRANCIS** - Absolutely.  We commenced by making that observation; in a nutshell it is our point of view that it is the individual's decision and that, because MS is a condition that exhibits itself in so many different ways, our stance is that the individual should have the opportunity to make an informed choice and we recognise that currently the legislation does not allow for that to occur.

**Ms O'CONNOR** - Do you recognise also that under Australian law now there is discrimination against people with disabilities, because it's not a crime to attempt or to commit suicide but it is a crime to ask someone to assist you if you're physically disabled with MS or a terminal illness or any other physically disabling disease?

**Ms FRANCIS** - That hasn't been articulated but I think it's the sense of understanding that at the moment they're denied that choice because of their physical incapacity.

**Ms O'CONNOR** - I came in earlier when you were talking about some of the feelings amongst the people you represent.  Could you flesh that out a little bit more?  Has there been discussion within your society, not just at the board level, but amongst your members, about this issue?

**Ms FRANCIS** - Not structured discussion.  It has not been an issue that has been brought to the fore purposefully.  Lynsey's role is also as a case manager for our society and in carrying out her role obviously there is the opportunity to recognise that this is an issue that may perhaps be best brought to the fore, and supported discussions occur at that level.

**Ms SPAULDING** - I spoke with our counsellor about this issue briefly on Friday and in her experience certainly something that comes up time and time again is the fact that people don't have control over what is happening to them in the progression of their disease and issues that affect every aspect of life:  employment, family life.  With MS it usually affects people in the prime of their lives, between the ages of 20 and 50, so there are a lot of issues around all sorts of life matters.  So the capacity to have some control over that aspect of their lives, when they have no control over anything else, is an issue that comes up in counselling a lot, as well as in our case management practice.

**Ms O'CONNOR** - I want to pick up briefly on something that Ruth was talking about before, that towards the end of life you can make a choice to have treatment withdrawn.  Do you see that there is any major difference between that act of personal autonomy, where you choose not to have treatment or to have treatment withdrawn, and that next step where you might go to the GP to ask for assistance?  In your opinion, what is the real difference there?

**Ms SPAULDING** - I think the difference is that if someone withdraws treatment, say with MS for pneumonia or another life-threatening infection that can happen for some people with advanced MS, there is always the possibility that death may not occur because antibiotics have been ceased or whatever treatment recommended hasn't been commenced, so I think there is an enormous difference between the two.

**Ms O'CONNOR** - But the act of will is not dissimilar, is it?

**Ms SPAULDING** - No, it is not.

**Ms FRANCIS** - Certainly that feature of autonomy is still there but I guess it comes back to the other element of the title, and that is dying with dignity.  The removal of treatment does not always guarantee dignity and often it would be the case that the personal pain that is experienced is exacerbated considerably.

**CHAIR** - Is there anything you would like to say in conclusion?

**Ms SPAULDING** - Not from our perspective.

**Ms FRANCIS** - Thank you for the opportunity to provide this feedback and also for the scope to provide further feedback in terms of the numbers that we represent and also the nature of the conditions and likelihood of pain and the other conditions associated with those.

**CHAIR** - That information might need to come through fairly soon, too.

**Ms FRANCIS** - I can appreciate that.

**CHAIR** - Heather, thanks very much for joining Lynsey this morning.  We appreciate the provision of your information to our inquiry.  Thanks very much.

**THE WITNESSES WITHDREW**.

**PROFESSOR JEFFREY MALPAS**, PROFESSOR OF PHILOSOPHY, UNIVERSITY OF TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** (Mr Finch) - Thanks very much for coming to present here today. We have until 11 o'clock for your evidence but we will see how we are travelling at that time. The intention is to allow you to present and then we will follow on with questions.

**Prof. MALPAS** - You have the submission we provided which is a joint submission from Professor Lickiss and myself. Obviously I am more the expert on the ethical and philosophical sides so questions relating to more clinical aspects of this matter would be better directed toward Professor Lickiss, but she and I have been working together for quite some time now on a range of issues in medical ethics as well as in what you might think of as a broader field of medical humanities. My interest here is partly in the ethical concerns but also partly in a set of broader concerns about how we think about human beings and how we think about human values, and I think that is particularly important not to lose sight of in this debate.

There are a couple of key points we would want to make here. One of the most basic ones probably concerns the issue of autonomy, because I think one of the most common arguments advanced in favour of physician-assisted suicide or voluntary euthanasia is that it somehow affirms individual choice or autonomy. This claim is one that I think rests on some misunderstandings and they are misunderstandings that have become increasingly discussed in some of the philosophical literature partly as a result of Onora O'Neill's work. Her lectures on trust have been particularly important, as is her book on autonomy and, as she points out, very often the notion of autonomy that is used in public debate, sometimes in some philosophical debate, is an extremely narrow concept and often one that is not particularly well worked out.

O'Neill points out that in fact a narrow concept of autonomy that is too individualistically focused is actually incoherent and the reason for that is that choices, even individual choices, always affect other choices. It is never just a matter of deciding we are going to affirm one person's choice; in fact as soon as we do that we automatically affect the choices other people make. So one of the arguments that O'Neil makes - and this, as I say, has been quite influential in much of the bioethical literature since she wrote - has been that we have to have a more non-individualistic conception of autonomy and she bases that in ethics and that is her particular interest. I think quite generally one can see how if we think of autonomy in too individualistic a fashion, we get into serious difficulties.

When we are talking about physician-assisted suicide, I think that is particularly important because we are not simply talking about the choice of one individual in relation to a set of things that only concern them. We are talking about an individual who requests of another individual that they perform an act for them. The act that is being performed is a particularly significant act; it is not simply the provision of a service and it is not simply the provision of some good. It is an act that consists in that other person killing the person who has made the request. That is a fairly major request to make of somebody else.

For me, the rock-bottom question when it comes to this issue - in fact it is a question that is at issue whenever we talk about one human being killing another - is what does that act imply about the sort of community we are? What effect does that act have on the moral status and moral feeling of the person who performs the act? That is something that is not often discussed in these forums. But it is a very important and absolutely fundamental question. It is a question that is very often addressed by those who are working in exactly this area.

One of the most interesting things about this debate is that if you look at the public surveys that have been done, you will see that there is widespread support for some form of voluntary euthanasia amongst the public. It varies from country to country. Often it is difficult to know what to make of that because there is a great deal of confusion about what voluntary euthanasia really means. There tends to be a mixing up of issues to do with, for instance, advanced-care planning and advanced-care directives with issues of voluntary euthanasia. If you look at those surveys and at the way in which opinion divides up, those who are most unhappy about the idea of physician-assisted suicide are typically those who are most involved in palliative care, in dealing with dying patients. Very often they come from that group of people from whom one would also expect to take the individuals and expertise that would be needed in order to enact any system of physician-assisted suicide. I think that tells you something quite important because it tells you something about the feeling and the concerns of the people who are most involved in this process in the first place, and I do not think that should be discounted.

Certainly a lot of the anecdotal evidence is that those doctors who do feel that they are in positions where they are requested to provide the service, find it a very difficult act to perform. There is considerable evidence that it has quite significant psychological effects on the individuals concerned.

Norelle and I have been talking about this issue for some time now to many of the leading people around the world in this area, particularly those who are involved in palliative care. So, as you will see from our submission, we have been in discussion with Margaret Somerville in Canada and also Geoff Hanks in the UK. Recently we have had some correspondence with doctors involved in palliative care in Switzerland. So we have a little bit of a feel for the way in which in the Dignitas program is viewed within Switzerland. More recently, I have also had some correspondence with Professor Hank ten Have, who is in Holland, who is the head of the ethics unit at UNESCO. He has some interesting views on the Dutch situation.

So our submission is grounded in a fair deal of familiarity, both with the philosophical side of this but also I think, most importantly, with the expertise and knowledge of practitioners in the area as well.

**Ms FORREST** - The Dutch palliative care specialist you spoke to, do you have any references to him?

**Prof. MALPAS** - I do not have any reference to Hank ten Have's work, but I can direct you to references on that. One of the important things to understand about the Dutch experience is that one of the reasons voluntary euthanasia was legalised in Holland was primarily because palliative support in Holland was extremely primitive and is now, in fact, improving. One of the points that Hank ten Have made to us is that, as palliative care support has improved in Holland, access to physician-assisted suicide services has declined and there is now a bit a debate in Holland about some of that legislation and so on. I can certainly talk to Hank and see whether he can get us some more detail. This is very much on the basis of personal correspondence that we have been engaged in. I can certainly see whether I can get some more data on that.

There is a considerable amount of discussion amongst doctors and palliative care specialists around the Dutch situation and there are certainly some interesting views that come out of that in terms of the experiences of doctors. One of the difficulties in this area is getting hard data because so often the data that is submitted is heavily influenced by the values of the doctors or the citizens who are providing that data. That is a real difficulty in trying to get statistical evidence, whether in terms of views or I would suggest even in terms of likely incidents of physician-assisted suicide in various countries.

**Mr GAFFNEY** - One of things that was in Rob Syme's book was that there are some doctors in our society who have made the decision that they are comfortable with assisting people to suicide. Dr Syme said that a lot of the doctors have the knowledge and know-how, so if they are ever put in that same situation they have the capacity to end their life because of the pain tolerance. I know it is only a minimal percentage of people in that category that have stated they have that capacity and knowledge, but the everyday bloke on the road does not have that capacity and does not have that choice due to their lack of education or ignorance or ability or capacity to access those drugs or whatever.

**Prof. MALPAS** - I think that is an over-simplification. It leaves out a large number of other factors. Certainly not every general practitioner would actually have the knowledge to end their own life if they were in a situation of intolerable pain or if they were suffering a serious illness. Again, some of the interesting data that has come out in relation to this is that in some cases, even when a doctor is performing euthanasia, that can still go wrong. The fact that a doctor is performing it does not mean that it will end the person's suffering. That is particularly true where you have conditions that are complex in themselves, where there might be other medication involved. Even the administration of morphine can be complex. We discussed some of Dr Lickiss' cases. She had a case recently - I should be careful about the case because I do not know all of the clinical details - of a patient who was suffering a severe form of cancer. The usual administration of morphine was not having any effect. Probably, I suspect, additional morphine would have only complicated and made the situation worse. The decision was made to switch to an older form of pain relief in order to deal with the case. Many doctors who did not have the level of expertise that Dr Lickiss has would not have been able to make that decision or would not have made it in the right way.

I have certainly read some case reports of doctors in Holland, for instance, who have not understood complications that can follow from the administration of morphine and who have decided as a result that the patient was in intolerable pain and have euthanased. They have then discovered later on that in fact there was a quite simple procedure that would have alleviated the pain, would not have required euthanasing a patient and would have allowed the patient to carry on in reasonable comfort. Very often the sorts of cases where euthanasia is likely to be invoked are also cases that are hedged round with other complications and where it is not just a simple matter of, 'I am a GP, I know how to do this and therefore I have power that other people do not have'.

As a general argument that seems a dangerous argument to be making. We all have differences in terms of our capacities, knowledge, education and expertise in relation to a whole range of different things. I do not think that is a reason for saying that there is some injustice or unfairness about what we can and cannot do. We all have different sorts of burdens to bear and we bear them in different ways.

**Mr GAFFNEY** - How would you respond to point 12 of the 1998 review where it said, 'The committee recognised that in a small percentage of cases palliative care is ineffective in relieving all pain. However, whilst regrettable, this is not sufficient cause to legislate for voluntary euthanasia'. This means that there is a section of our community that is in pain and suffering and yet, going back to your opening paragraph about individual choice and whatever, is that acceptable in our society, that we don't allow those people to leave the world in no pain?

**Prof. MALPAS** - I think you have to be very careful that you don't oversimplify the situation. There are a number of factors there. Firstly, one of the reasons why it might be that we decide that we don't end those people's lives, that we don't kill them as a way of relieving the pain, is simply that there are other costs associated with that act, and we might decide that those costs are not acceptable. That is one of the considerations. Another consideration I would put to you is that, just as the attempt to relieve suffering by killing somebody might relieve suffering in some cases, we also know that there are some cases in which it will increase suffering. It is arguable as to what the percentages are, but there is certainly evidence that that is the case. It's not a simple matter of being able to say, 'If we were able to kill these people then that would reduce the suffering'; it is by no means as straightforward as that.

The idea that seems to be motivating this is that we should be able to control all suffering, we should be able to eliminate it. I am now speaking particularly as a philosopher who is not just interested in this issue but also in a range of issues. One of the deepest sources, I think, of many of the elements that we face is the idea that we can control everything. We can't; we can't control our own suffering. There are some forms of suffering that we find very hard even to quantify, to identify. The idea that we could have a perfect world in which our medicine would be so perfect that nobody suffers, I think is probably an impossible and incoherent idea. It is not a matter of accepting that there is some suffering that we can't do anything about, so much as accepting that suffering is something that we're never going to be able to get rid of. We're not going to be able to get rid of it because that is part of what human life is about. That doesn't mean that we have to accept suffering, that we have to be quiescent in relation to it, but it does mean that we have to be careful about the idea that we can control every aspect of our lives.

**Mr GAFFNEY** - I appreciate that. You have mentioned the word 'simplified' and I appreciate that position, but I would say that sometimes suffering is different to intolerable pain. We mustn't oversimplify the pain that somebody would be in. This bill would say, 'I am in intolerable pain. I choose to end my life because I can't put up with it anymore. I want somebody to be able to do that and whoever does that for me, I don't want them to be a criminal. I want them to have the safety of the structures of our society so I can do that'.

**Prof. MALPAS** - Notice what you're doing there. First of all, what is being asked is not just an ordinary service. You're asking that somebody else take on the burden of killing you. That is a very significant burden. Generally speaking, it is the heaviest burden one could possibly place on somebody. In relation to the issue of suffering, there is a distinction that is very often made between, for instance, pain and suffering. Professor Lickiss and I ran an international colloquium on suffering two years ago. One of the features very often that is taken to characterise suffering is that suffering occurs when one's own sense of self-worth is dangerously brought into question. So we suffer when the self is seriously affected in some way. That means that suffering doesn't only occur in cases of physical pain; it occurs in many different sorts of circumstances. Usually when we talk about intolerable pain we mean some extremely high level of physical pain, although it seems to me very often there can be forms of intolerable pain that are not physical in nature either. These situations are incredibly complicated. I am trying to simplify the situation in one sense, however, and that is to keep us focused on the fact that what we are asking when we ask a doctor or somebody else to assist in our own death is for that person to take on the burden of killing us. I think that is really important to keep in mind.

**Mr GAFFNEY** - In the Oregon model, where they have the tablet that the person can take home, which is supplied, do you see that we are disassociating the person, as in the doctor, being the provider? I think there were 341 cases in the last 10 years where they have taken that tablet but that decision becomes more the person's and not society's?

**Prof. MALPAS** - That is a more complicated case. Ethically, depending on the circumstances and depending on the social content, it may well be that the physician might view that as a situation where they are in some sense performing the act, but it is a very complicated case. It does rest, if you like, in an area between the straightforward cases of physician-assisted suicide and the cases of straightforward suicide. There is a wide range of advice that one person might give another in terms of enabling that person to carry out an act that will cause their death. It is a complicated case.

The sorts of cases that most concern me are cases where physicians do directly intervene in terms of administering the drug that will bring about death. Those are the cases that it seems to me are central in this discussion.

**Mr GAFFNEY** - I notice here that you have referred to the EAPC taskforce report. I am asking whether, if you include that in your paper, you are agreeing with some of the points they highlighted.

A second point is that if euthanasia is legalised then we have less time for better palliative care methods. It has been suggested to us that in Oregon, for example, that has been not the case because they were so worried about it that more finances and more resources were placed into providing better palliative care as a result of voluntary euthanasia coming into the States.

**Prof. MALPAS** - I think it would depend on the case. The Oregon case is a very unusual one in lots of ways and it may well be the case that that has occurred there. That should not be seen as an argument, of course, for physicians to assist with suicide; that would be one important conclusion to draw. The other conclusion you might draw is that you might want to look at some other cases.

A lot of the anecdotal evidence, certainly from doctors who have worked in the Dutch system, suggests a tendency to make use of euthanasia rather than look to palliative care techniques. I think that is a very widespread experience and you can see why that would be. It would not necessarily need to be the case that your palliative care services would get worse. The Dutch case might be taken as an example of a situation where that was not so. If you accept Hank ten Have's evidence then what has happened in Holland is that at the same time as they have had physician-assisted suicide, they have also had a situation where palliative care was improving. You might argue that was because in Holland palliative care services were of such a poor level to begin with so, again, it is difficult to know how to judge.

One of the real practical concerns one might have is that, even if palliative services improve, there might be a greater tendency on the part of doctors to make use of euthanasia techniques rather than to make greater use of palliative care services. I think that is a major concern on the part of some palliative care specialists. For instance, in Switzerland the palliative care hospitals generally speaking will not allow any of the Dignitas literature into their facilities. So there is obviously a set of concerns here. I do not know if one can make a clear decision either way. Again, this is an indication of how complex these issues are.

**Ms O'CONNOR** - You were talking before about oversimplifying and to be careful about presuming that personal autonomy issues should outweigh the wider potential impacts on the community.

**Prof. MALPAS** - There is a very simple view of what personal autonomy is. It is often a view that treats it as if it were just a matter of each individual being able to choose, no matter what their choices are.

**Ms O'CONNOR** - I understand that, but then if we can just peel back to the individual sufferer, who is the focus of this bill, how do you ethically respond to a legal framework that currently can only be said to prolong their suffering because we do know - and even the palliative care experts will tell you this - that there are some people for whom palliative care does not provide relief. These people are in profound pain and suffering, what is the ethical response, in your view, to their situation?

**Prof. MALPAS** - I might say first of all all of the palliative care specialists I have worked with - including Professor Lickiss, Professor Hanks and many others - have repeatedly said they have not encountered a patient for whom they felt the only option was euthanasia. I think that is an important point to make.

**Ms O'CONNOR** - No, but have they said they have encountered patients for whom palliative care does not provide relief?

**Prof. MALPAS** - There are some patients for whom even the best efforts cannot completely control the pain. There is no doubt about that, but that follows on from the point I was making before about the fact that one of the important things we have to recognise about all our practices is that we are never in complete control. We cannot control everything and I would say that is as true of physician-assisted suicide as it is true of palliative care techniques. That is very important. That has an impact on what we say about those individuals who are in severe pain; we can do our best for them, and that is all we can do, we cannot do better than that. One of the over-simplifications here is to assume that the only thing that matters here is one individual in pain; there is never one individual in pain. What we are typically talking about is an individual who stands in relation to other individuals who might ask another individual to carry out an act in relation to their own life. We are not just talking about individuals. That is one of the reasons why that particular construal of the autonomy argument is so problematic because it assumes there are just individuals.

One of the features of human life - what makes us human beings - is actually our relational character and the way our lives are embedded in relations with others. That means that when one individual kills another individual it has implications for that individual's concept of themselves, and it has implications for the rest of the society - it has implications for the people who experience that act and who stand around it. Of course, we can have a concern and compassion for the particular suffering that an individual feels and we can do our very best to try to manage that suffering and to try to relieve it, but there will be some cases where we fail.

**Ms O'CONNOR** - Can you see that that statement has an element of heartlessness to it?

**Prof. MALPAS** - I would strongly object to that. That is not heartlessness. There is a heartlessness that says, we can control everything and when we cannot control something we will kill you. To me, that seems to be a deeper form of heartlessness because it fails to understand the way in which, as it were, compassion does not require and cannot require that you control everything for the individual. It requires that you do your very best, but the point beyond which compassion does not take you, is the point at which you say, 'therefore I will kill you even when you ask me to'.

**Ms O'CONNOR** - Or therefore I will meet your desperate desire to be assisted to end your life.

**Prof. MALPAS** - No. It is very important to understand the nature of the act; and the act is an act of killing. That is one of the reasons this is such a fraught ethical area, it is an act of killing and the act of killing, as with all acts, has an effect on the one who performs the act and on those who witness the act - not just on the one who is the victim of it. That is one reason why in our society we have such a prohibition against killing because it has such a strong ethical and moral impact on the agent and not just on the victim.

**Ms O'CONNOR** - Professor Malpas, I put to you a paper that was published in the *Medical Journal* in 2001. They surveyed 992 eligible general surgeons, they had a 70 per cent response rate, and 247 respondents, that is 36 per cent, reported that for the purpose of relieving a patient's suffering they have given drugs in doses that they perceived to be greater than those required to relieve symptoms with the intention of hastening death. Do you accept that right now in Australia and possibly all over the world doctors acting out of compassion are administering medication in such dosages knowing that it will hasten the death of the sufferer?

**Prof. MALPAS** - I certainly cannot assent to that statement because it contains too many additional claims and qualifications. I assume that you are referring to the Australian survey that was done a few years ago?

**Ms O'CONNOR** - 2001 in Australia.

**Prof. MALPAS** - If you have a look at the evidence from around the world there are varying levels at which it is thought this happens. It is recognised that the level of reporting is hard to ascertain because there are all sorts of considerations involved here. One of the difficulties with any survey is that it is always hard to be sure that the way the respondents understand the questions is the way in which they were intended.

If you look a the latest evidence from the UK you will see that the UK observes that there is certainly a higher reported rate of physician-assisted suicide, whether legal or not, in Holland as well as in Australia and in one or two other countries. In reports from the UK, I think the latest evidence is that this is not reported as something that is being undertaken by UK doctors. So there is an enormous variation, depending on the circumstances.

**Ms O'CONNOR** - But can you understand how, because it is a crime, reporting is actually an issue?

**Prof. MALPAS** - Reporting goes both ways. If you look a the reports that are done by pro-euthanasia lobby groups you will find it goes one way and if you look at the reporting done by anti-euthanasia lobby groups it goes another way. It is not just a matter of whether it is a crime. It is also to what extent different sorts of processes are being understood as instances of voluntary euthanasia. That is one of the difficulties here. There are cases where doctors might in fact administer pain relief thinking it is a possibility that this might kill the patient but that is not the intention of the relief.

**Ms O'CONNOR** - This paper clearly says that there are doctors who administer the medication with the intention of hastening death.

**Prof. MALPAS** - I am not convinced of some of that data simply because it does -

**Ms O'CONNOR** - They actually go through the methodology, the survey instrument that they used and the questions and they have been very precise about how they came forward with the data.

**Prof. MALPAS** - There is no doubt that some of this is happening in Australia and it is happening at varying rates around the world. In some places possibly it is not happening.

**Ms O'CONNOR** - Is that manslaughter or murder, in your view?

**Prof. MALPAS** - I think it would be inappropriate for us to call it murder because it seems that the intent - well, I don't know the cases.

**Ms O'CONNOR** - But broadly speaking we know that the act is happening.

**Prof. MALPAS** - If we know then we may well know that there are doctors that are killing their patients.

**Ms O'CONNOR** - Out of compassion?

**Prof. MALPAS** - Hang on, we know there are doctors killing their patients; we do not know what the motivations are. That is one of the really problematic issues here. We do not know what the motivations are.

**Ms O'CONNOR** - But 36 per cent of these respondents said the motivation was to relieve suffering.

**Prof. MALPAS** - I do not think that we know clearly what the motivations are and I would rather not speculate on what the motivations are.

**Ms O'CONNOR** - These numbers are pretty hard. It was an anonymous survey -

**Prof. MALPAS** - Hang on, what do you want to conclude from that? What you might conclude is that we need to do a lot of work in this country in order to improve the understanding of palliative care and of advanced care directives. I have no doubt that if we actually brought in an institutional framework that enabled advanced care planning directives or advanced directives to operate then that would actually reduce some the difficulties here. It may be that some of these doctors are not well aware of the other options that were available to patients in those situations. We simply do not know.

**Ms O'CONNOR** - You would think that general surgeons would be aware of the other options.

**Prof. MALPAS** - They may or they may not, particularly in cases where we have patients with difficult conditions to manage. I do not think that that material provides us with any clear-cut evidence on which we can make a legislative decision.

**Ms O'CONNOR** - We have a situation which, on hard data published in a highly credible publication, tells us that around one-third of the respondents confess, essentially, under anonymity that they are administering drugs with the intent of hastening death in order to relieve suffering, so what we have is an unregulated framework right now where in fact there are acts of non-voluntary euthanasia taking place in Australia today.

**Prof. MALPAS** - That may well be the case, but that doesn't mean we simply legalise the acts that we are concerned about.

**Ms O'CONNOR** - The acts that are happening?

**Prof. MALPAS** - Yes. That is an obvious non-sequitur in terms of an argument. What it might lead us to do is really reflect on what is happening and consider why it is happening and then look at what options are available to us. I would suggest there are a number of options available to us, short of physician-assisted suicide being given legal authorisation.

**Ms O'CONNOR** - In your view, is terminal sedation or an induced coma a better solution for the patient than quick relief?

**Prof. MALPAS** - That's not the only solution we're talking about. Again, there is a real tendency here to want to simplify matters. Different cases need to be addressed on their own terms. One of the institutional things we can do, and which we have not done, is to introduce a proper system of advanced care directives and advanced care planning. Anecdotally, in talking to many people who ask me as a philosopher, 'What's your view on this matter?', they automatically assume, because many ethicists and lawyers who are not involved in palliative care are in support of physician-assisted suicide, that I will be as well. They are surprised when I say that I'm not. We then talk about the issues and I point out that one of the things that I'm particularly keen on having institutionalised is the system of advanced care directives. They then say, 'I hadn't realised that that's what you meant. I was thinking of that as being part of the euthanasia package'. I think there is a real distinction there.

The fact that we have this happening tells us there is an issue that needs to be addressed. The question is, 'What do we next do?', and I'm suggesting that it would be a serious mistake and a severe oversimplification to suggest that what we do is simply legalise the problematic behaviour. In fact, if we did I would suggest we would be pushing the real problem under the carpet because the real problem will require a much broader and more complex set of arrangements in order to address it. It will probably require something like advanced care directives; it may also require some additional work in terms of our palliative care services. There isn't going to be one single solution, and physician-assisted suicide is certainly not the silver bullet that will solve this problem.

**Ms O'CONNOR** - With respect, no-one is suggesting that it is, but that it be part of a range of options for people suffering from terminal illnesses.

**Prof. MALPAS** - Very often the argument here is presented in terms of 'This is being done. This is the solution'. I am suggesting that not only is it not the solution, there are a number of other solutions. One of the reasons this might be the last solution you would look to is that it gives rise to a range of additional problems. It has serious ethical concerns around it. There are serious issues about how we distinguish between different sorts of cases in which it might be allowable and in which it might not. Just going back to Onora O'Neill, one of her concerns is the issue of trust. There is a real concern to what extent ordinary people might be willing to trust a medical system in which one of the options is that they might be killed if it is judged that they are in intolerable pain. Interestingly, I think it is significant to note that in many vulnerable communities the idea that physician-assisted suicide might be legalised is very often an issue that they are very concerned about. I think this is a complicated set of issues.

**Ms O'CONNOR** - We heard evidence this morning from the people representing the MS Society that a lot of their members feel quite strongly about that personal autonomy issue.

**Prof. MALPAS** - Again, as Onora O'Neill says, one has to be very careful about how one reads public opinion on these matters. I couldn't hear all of the discussion, but one of the things that seems evident is that there is a need for much more public debate on this issue and that many of the opinions that people very often give on this issue are not as well informed as we would like them to be. Once again, there is a range of other techniques that we could use here that might well allay some of the fears that people have. I think one of the biggest fears for many people is the fear that they will find themselves in a hospital in intolerable pain and doctors will do everything they can to keep them alive. Advanced care directives are one of the methods we can use to try to prevent that from occurring. The vulnerable groups I was thinking of were, for instance, indigenous groups, for many of whom there would be concerns about that, perhaps not in Tasmania, but certainly in other parts of the world.

**Ms FORREST** - I wanted to ask one more question related to that paper. I have looked at it and wanted to take the professor to the issue of a doctor's intent to hasten death.

You cannot tell from the paper, but if someone is administering a drug to relieve suffering in a compassionate manner - and the doctors here are surgeons, who are not generally involved at the coalface of people dying - so if they are giving a drug out of compassion to relieve suffering with the intent of hastening death, in my mind that tells me two things. One is that the patient is dying, because if they are having to hasten death they are already dying, and you are giving a drug here to relieve suffering so it would be a drug intended to either relieve pain, delirium or dysnia - a whole range of drugs that could be used in that setting, as opposed to giving them a big whack of propofol or something. Are we talking about the same thing here? This is one the issues I have with that particular paper - that maybe we are not talking about the same thing.

**Prof. MALPAS** - Yes, I'm not sure if we are, with the issues you're raising are the reasons I am cautious about what conclusions to draw from that paper. You're familiar with the issue of 'double effect' in the administration of pain relief.

**Ms FORREST** - Yes.

**Prof. MALPAS** - Whether a doctor interprets that as meaning that to some extent they might be attributed with the intent to kill is a difficult one. Whether they really should be taken as having that intent is not clear-cut. I think these sorts of issues are seldom as straightforward as they appear. I know I am saying quite often that this is more complicated, but I tend to agree with you that it's not at all clear how we should interpret some of that evidence.

I might say, too, in academia we publish papers all the time in respected journals, but that does not mean we necessarily agree. No paper that is published is ever 100 per cent accepted by everyone within the community; we argue about some of those things. What one looks for is a body of agreement across a range of different pieces of information and that's why I think it is important to read that piece of evidence in the light of some of the other surveys that have been done. That is why I referred to the Seale paper, for instance, from the UK which was done I think earlier this year, which also has evidence not only on medical practitioners' views of euthanasia but also some evidence on what are the reported incidences of this sort of thing. So I think it would be a mistake to just rely on one paper. It is important to read it against the body of other evidence, and it is very difficult sometimes to interpret results.

**Mrs BUTLER** - I am very interested in your ideas about an advanced care framework or a framework to develop that. Can you speak to what you have in mind for that framework? Is there a central point?

**Prof. MALPAS** - This is probably something on which Professor Lickiss is better qualified to speak because she has been much more closely involved in developing this sort of documentation and we can provide some examples of the sorts of documents that have been used and which we think could work here. There are two sorts of things. One is the advanced care directive or the living will whereby somebody sets out - basically it's a withholding of consent. It's a statement that they do not give consent to a range of procedures that might be intended to prolong their life in certain conditions. Typically that is a document that is drawn up when the patient is perhaps in good health, perhaps in a situation where they do not anticipate any illness, but it will then come into effect when they're in a position where they can no longer make those decisions for themselves. So that's one part of it.

The second part is an advanced care planning system which enables us to put in place default settings, procedures and so on as to how we will generally care for patients with certain sorts of conditions and prognoses. So it's really a two-pronged approach and, as I say in the submission, this is not something that just Norelle and I are proposing. It's a proposal that has come from elsewhere. I refer to in one of the major reference works in bioethics that suggests that this is actually the best way to try to resolve some of the disagreements and confusions here. Certainly I can provide you with some examples of those sorts of documents if you would like rather than -

**Mrs BUTLER** - So you would still see the individual or the patient at the centre?

**Prof. MALPAS** - No, because this is something that will have to be worked out by the patient in conjunction with the people around them. All our decisions are like that; there are very few decisions that we can really make on our own. So the advance care directive would be a document that was formulated. Obviously it is the patient themselves who signs off on it, in the same way that we sign off on a will, but ideally it is a document that would have to be formulated in relation to the other people around them. It mean, it's no good my drawing up an advance care directive in which I say, 'I don't want this, this or this done', I don't consult with my children about it and when it comes to it and I'm there, unable to speak or make a decision anymore, they want to somehow override the document. So I think it's really important that those sorts of decisions should involve other people.

Whether you want to have some additional safeguards in them, I think you might want to consider that, but if we treat them much as we treat wills then it seems to me that we have already some precedence in terms of how we might go about things. But, as I say, probably the best thing to do is provide you with some of the documents that we have in mind, some model documents.

**Ms FORREST** - Jeff, you made some comment a little while ago about the impact on those involved in euthanasia, the doctors involved, whether it was physician-assisted and even with a situation where in Oregon, they can take the drug home and potentially give it, so you have the family or anyone else involved in that. Is there any research or anything that shows those impacts?

**Prof. MALPAS** - I'm not sure. It's something that I probably should have looked at more. I don't know. Most of the discussions focused on more direct physician involvement in this sort of thing and I don't know of any research, but I'm certainly happy, if you would like, to see whether I can find out some more on that and send it on to you.

**Ms FORREST** - That would be helpful.

**Prof. MALPAS** - I guess one of the reasons why it hasn't been such a focus is that it does still require some autonomy, some capacity for action on the part of the patient themselves.

**Ms FORREST** - Yes, that one.  But the doctors who are actively giving the medication and those involved at that time - are you aware of research in that area as well?  Not just the ones who take it home themselves and take it, potentially.

**Prof. MALPAS** - Do you mean in cases where the doctor is actively involved?

**Ms FORREST** - Yes.

**Prof. MALPAS** - In terms of actual effect, a lot of it tends to be anecdotal and the reason for that is that it's very hard to do survey work on that sort of thing.  It's not an area in which you can get clear quantitative results, that's the difficulty, because we're very often talking about emotional and psychological effects.  Again, there is a lot of anecdotal evidence there and I would argue that there is a lot of philosophical consideration that would lead us to have concerns.  But the problem is constructing a survey or a piece of experimental work that would enable us to follow through patient cases where we're looking at the effects on the physician and, say, the family, where physician-aided suicide has gone ahead.  I don't know of any real research that has been done on that and, as I say, I think the reason is simply that it would be very hard to carry out.

**Ms FORREST** - I have read in some papers regarding the question of a doctor assisting that the first time was really tough and difficult and the second time was easier.

**Prof. MALPAS** - Yes, there's plenty of that but, again, that's anecdotal rather than quantitative.

**Ms FORREST** - It's hard to be quantitative with this.

**Prof. MALPAS** - It is, very hard.  I was taking your question as being directed at more large-scale quantitative surveys.  There is certainly a lot evidence that focuses on the anecdotal level and I can give you some references to some of that material as well and we have certainly looked at some of that in the course of preparing this submission.  A lot of that evidence is what sways many of palliative care physicians and, again, it's anecdotal, but very often the evidence is that doctors do find it hard the first time but easier as they go on.  There is a concern about the degree to which doctors become, as it were, desensitised, and that actually is a really major concern because it's exactly that process of desensitisation that has been seen as lying at the heart of many cases much more spectacular where the desensitisation to begin with has led on to much worse cases of malpractice.  There are some very unpleasant studies of the sort of thing that has gone on in several cases.

**Ms FORREST** - Not just in this area but other areas of medicine?

**Prof. MALPAS** - Yes. There is a huge amount of data and I hesitate to even bring this up but there is a huge amount of work done on the way in which, for instance, in the 1930s German doctors became desensitised under a series of procedures that were intended first of all to introduce euthanasia for patients with mental or physical disabilities and so on and so forth. The reason I hesitate is that that is such a very different sort of case. What is similar is the impact of desensitisation and there is a lot of work on that, there's no doubt about that.

**Ms FORREST** - That would be interesting to see that.

**Prof. MALPAS** - Yes.

**Mr GAFFNEY** - I found this very interesting. I am wondering - and it is probably another hour's worth - about your philosophical viewpoint on our society accepting suicide as not being a criminal act. You mentioned suicide before and I know that we do not have another hour for it.

**Prof. MALPAS** - This is something I have given quite a bit of thought to. I am not religious. We happen to teach the philosophy of Buddhism in the School of Philosophy but I'm not a Buddhist so I don't hold any particular religious view and I don't think a religious perspective is at all helpful in this discussion.

Suicide I think is a really interesting issue and one that I have often talked about to first-year students. Albert Camus said there is only one truly philosophical question and that is, 'Should I or should I not take my own life?'. I think the question of suicide is a really interesting example of the way in which individual choice can mislead us. I am not suggesting that suicide should be made illegal because I think that would not help us either, but one of the things about suicide is that I think in many ways it is an act that comes about due to - certainly it can come about in lots of cases because of -

**Ms O'CONNOR** - Mental illness.

**Prof. MALPAS** - Mental illness, but there's also an issue about the nature of the mental illness.

**Ms O'CONNOR** - But how could any one of us who is not suffering from the mental illness make any assumption about what is happening inside some other person's head that might lead them down the path towards contemplating suicide?

**Prof. MALPAS** - We make assumptions and judgments about that all the time, just as we make judgments about other people all the time.

**Ms O'CONNOR** - But it's in the absence of true knowledge, isn't it, about what's happening inside the sufferer's head?

**Prof. MALPAS** - Careful - as soon as you use terms like 'true knowledge' to a philosopher I start to get very, very worried!

*Laughter.*

**CHAIR** - Time is of the essence, I'm sorry.

**Prof. MALPAS** - Look, very simply, that we do and can understand other people is a presupposition of our being able to live in society, and we do understand and know other people. This is something that I've actually written a great deal on and it's a very basic and fundamental philosophical issue, but I don't think there is any basis on which we can question our ability to know other people. I do think one of the most problematic elements that lead to suicide is a sense of alienation and isolation. That's important because it indicates the way in which suicide comes about through a failure of our capacity to engage and relate to other people. There is a huge body of research that says the single most important thing for enabling human happiness is, in a word, love, or put in more complicated terms, our relationships to other people. That is what makes us human and this is the fundamental basis on which I teach ethics and on which I teach philosophy: it is our relationships that make us human beings.

When those relationships are harmed or destroyed, then we lose not only a sense of connection to others but we also lose a proper sense of ourselves. Suicide is one of the things that can lead us to. Whether we get that sense of isolation due to mental illness, whether we get it due to social circumstance, whether we get it due to a whole range of other factors, it seems to me that that's very often what happens in cases of suicides. That is one of the reasons, however, I think physician-assisted suicide is problematic, not necessarily because of the suicide of the person concerned but because of the way in which it implicates the relationship to the other and the way in which it has an effect on that other. I think that is the fundamental reason we should be very, very careful about any legalisation of killing within our society.

**CHAIR** - Thanks very much, Professor. We appreciate very much your time.

**Prof. MALPAS** - Thank you, and I will get back to you on a couple of those other issues as well.

**THE WITNESS WITHDREW.**

DISCUSSION WITH **PROFESSOR NICHOLAS TONTI-FILIPPINI,** VIA TELEPHONE LINK.

**CHAIR** (Mr Finch) - Hello, Nicholas, it's Kerry Finch and our committee as we have it today with five members - Ruth Forrest, Michael Gaffney, Heather Butler, Cassy O'Connor and myself here assembled. It is almost 11.10 a.m. and we have allocated 30 minutes for you so we will see how we go with that time. I will hand over to you to make any presentation that you feel you would like to us. Thank you very much for your submission, which is submission 130 of about 500 at this stage.

**Prof. TONTI-FILIPPINI** - Thank you very much for giving me the opportunity to do this by teleconference. I know it is harder on you to do it that way and I am very grateful. I will not go over what is in my submission - it is a short submission and you would have read it - but my position is simply that I do not think it is in the interests of people like myself, people who are suffering from a terminal illness, to have the added pressure applied to them of it being possible to end their lives by requesting it. It changes our status in the community. Our lives become contingent upon our continuing to express the view that we want to keep living, and it imposes something of a burden upon us that if we are a burden to others then there is another option that we could end that by requesting the end of our own lives. That possibility changes the context in which we live and in which we're cared for. I am simply putting that view to you hoping that as members of parliament you will continue to protect people who have severe and terminal illnesses, and especially those who have chronic illnesses like I have. I think I would rather hear what you have to ask me in relation to what I've said in my submission, so I think I'll stop at that point.

**CHAIR** - I am assuming that your operation that you spoke about in your submission some weeks ago was successful?

**Prof. TONTI-FILIPPINI** - No, it was partly successful; they managed to get a wire down into the vessel they wanted to open but after three hours they had to stop because of the toxicity of the radio-opaque dye they use and the real-time X-rays. I'm actually going back in again this Thursday for them to have a go at trying to perfect the procedure, so I've had a fairly painful five weeks since then but I'm hoping that after Thursday things might improve.

**CHAIR** - We have had some evidence from Professor Malpas of the University of Tasmania this morning, in his submission and verbally, in respect of the impact that decisions about taking one's life has on the people who are needed to support that decision. Would you like to make a comment there?

**Prof. TONTI-FILIPPINI** - Obviously I haven't heard what he had to say so I'm not sure what to respond to but, as I understand it, the context you're talking about is when somebody is terminally ill and has dependants - is that the circumstance?

**CHAIR** - Yes.

**Prof. TONTI-FILIPPINI** - Well, that's exactly mine, I suppose. I have a 15-year-old and three children at university I am still supporting so I'm in a situation where there would be considerable pressure upon me to continue if I wanted to do the opposite in my own circumstance. I'm not sure what he was raising there.

**CHAIR** - He was talking about the effect more on people in the medical profession, the physician who was required to assist.

**Prof. TONTI-FILIPPINI** - That's right; it throws a lot of pressure on people. I was involved with a case that was written up in the *Medical Journal of Australia* in 1992, the Mrs M. case at St Vincent's Hospital where I was the ethicist, and I can talk about her circumstances that have been made public without identifying her because she was never identified, but in her circumstances she had two young teenage boys, 13 and 15, and a husband, she was dependent on a ventilator and she wished to have it withdrawn. That was exactly the circumstance; there was a lot of pressure on the treating team and they ended up acceding to her wishes, but only after seeking a psychiatric consultation to ensure that she was competent and so on.

It was a very difficult decision all round, especially for the medical personnel - I was only giving advice - and very difficult for the nurses. I remember that I was involved in talking with the nurses before, during and after the event, and some of the people who were most affected were nurses who were not around at the time it happened but who came back to work to find that she had died in these circumstances. It was very difficult for them to adjust to it. I remember one of the nurses saying, 'So she died because she was competent, then?'.

**Ms FORREST** - That's pretty profound, isn't it?

**Prof. TONTI-FILIPPINI** - Yes. My response was that she died because the only treatments we could offer her were very burdensome and she didn't want to continue with that very burdensome treatment.

**Ms FORREST** - It is Ruth here; I have a health background and that one smacked me in the face. Doing a psychiatric assessment to assess that lady's competency while on a ventilator would have been no mean feat. This bill we're looking at has a requirement to have a psychiatric assessment, so I'm just fascinated - no, I don't know what I am - I'm at a bit of a loss. I'm wondering how it works.

**Prof. TONTI-FILIPPINI** - If I can just talk about the psychiatric assessment, one of the things I had to learn in that case was that when people suffer from the condition she had, which was motor neurone disease, they can have an involuntary smile and that can be very misleading when you're talking to them. If you say something to them and they have this involuntary smile you may think they're agreeing with you when they're not, so that was one thing I had to deal with and had to have explained to me. Another thing from a psychiatric point of view was that she could speak; the ventilator did not stop her speaking because by putting a finger upon the apparatus where it went into her neck she was able to create the pressure that would allow her to speak in short sentences, so she could communicate readily. She was intelligent and able in those sorts of ways.

Her case was atypical because at one point she was able actually to walk around pushing the ventilator, not in the later stage but earlier, so it was atypical in that it affected her lungs before it affected her limbs and normally it is the other way around. Normally people become incapacitated and cannot walk first, but she was able to walk. Earlier she had been able to put the tube down to suction out the tubing and because she could control that that was fine, but a big change happened when she lost the capacity to do that. Someone else poking the tube down into her trachea was probably her major burden, that and the fear of the ventilator breaking down, because she had experienced respiratory distress. To have that awful experience of not being able to breathe and the terrible discomfort of having somebody else poke a tube down your trachea to suction out, for those of you who are not from a medical or nursing background, people in those circumstances cannot cough and so they get a build-up of phlegm in their trachea down towards their lungs and that has to be suctioned out and usually that happens about 15 times a day; in other words, about every hour-and-a-half somebody would have to come in and poke a tube down into her trachea and suction it off. It is very uncomfortable, very difficult and some people cope and some people find it very difficult.

**CHAIR** - Nicholas, a question now from Cassy O'Connor.

**Ms O'CONNOR** - Nicholas, you have just told a very profound tale from the observer of the sufferer's perspective. I want to put another one to you that was written to us by Barbara Glidewell MBS who is the Hospital Ombudsman, Director of Patient Relations and Clinical Palliative Care Specialist at Oregon State University, who submitted a short paper to the Archbishop of Tasmania in response to some comments that he made. I would like your response to this statement that she makes.

> 'The patient who is suffering and has an active terminal condition is in the process of dying. Many experience existential suffering as their sense of self, their autonomy and adult character, beliefs and values cause them to reject or loathe having to rely on others to meet their daily needs.'

- which is the case you just put to us.

> 'These are cogent, independent individuals with a terminal illness who choose not to endure emotional distress at the last breath.'

- and this is the nub of what she says, I think:

> 'On the this issue, those who are care-givers or observers often say, "Well, just lie back and wait for death to come, we will take care of you.".'

Barbara, with 11 years' experience in Oregon's death with dignity legislation, says:

> 'This is easy to say when you're not in the patient situation. One cannot know the terror and the fear of the exacerbation of symptoms patients know are oncoming and the disastrous effect on their psyche as they endure for others'.

What is your response, as an ethicist, to that perspective of the sufferer's situation?

**Prof. TONTI-FILIPPINI** - I think that the carer whose comments were offered in those circumstances was not doing their job properly.

**Ms O'CONNOR** - But that's a crude way of saying what palliative care is, isn't it? 'You lie in your bed and we will take care of you'.

**Prof. TONTI-FILIPPINI** - No. I have had a lot of experience with palliative care, both as a recipient of it and as someone who has been involved for a long time in the provision of it. That is not good palliative care and I would hope that that would not happen in palliative care. What you hope to do is to say to the patient, 'We, together with you, will manage the symptoms. We can offer you lots of alternatives in terms of managing symptoms while we try to keep you as lucid as we can and in control if we can.' So it is a matter of helping the patient to live with the dying process rather than just shutting down as that quote implied and having the carers take control. You do not offer to take control, as a palliative care nurse or physician, unless that is what the patient requests of you. But you do want to say to the patient that, with you in charge, we can manage these symptoms. When I lecture on palliative care, one image I use is the image of one of those square-shaped parachutes that you can control the direction of. In other words, you can make it land more quickly or more slowly and you can direct where it is going to land by the way you pull on the leads. I say that is the circumstance that we should see in palliative care, that the patient is sitting there in control, they are going to land and we cannot stop them having to land somewhere but we can control the rate at which they land, where they land and what sort of landing it is. That is, they can control that by directing what we do, as the carers, in that process. If that was said by a palliative care person, then it was not said by a competent palliative care person.

**Ms O'CONNOR** - Professor, you are talking about the patient in a palliative care situation always being in control and being in charge but that is not really true, is it?

**Prof. TONTI-FILIPPINI** - I am not saying always. I am saying that you give them that option as much as you can. You do know that they may lose lucidity and at that point where they can no longer tell you what they want, it becomes much harder to have them in control. But what you can say to them is that we will do our best to manage the symptoms and, while you can, we will do it and involve you in how those decisions are made, so you can direct what happens.

**Ms O'CONNOR** - Professor, are you aware of a paper that was published in the *Medical Journal of Australia* in 2001 and the title is, 'The intention to hasten death: a survey of attitudes and practices of surgeons in Australia'?

**Prof. TONTI-FILIPPINI** - I do not have it in front of me but I do recall the article.

**Ms O'CONNOR** - What is your response? Would you concede, given the statistics that come out here, that we have involuntary euthanasia happening in Australia today? One of the first questions asked was - and this is a survey of 992 eligible general surgeons of whom 70 per cent responded - have you ever, for the purpose of relieving a patient's suffering, given drugs orally or parenterally, by bolus or by infusion, in doses greater than those required to relieve the symptoms, with the intention of hastening the patient's death? Thirty-six per cent of respondents to that survey said that they had. Is that not involuntary euthanasia or is that manslaughter under the law as it stands today?

**Prof. TONTI-FILIPPINI** - Certainly that is euthanasia and it is active euthanasia because they are getting more than needed to relieve pain.

**Ms O'CONNOR** - But is that not manslaughter?

**Prof. TONTI-FILIPPINI** - Whether it is voluntary or not, I did not see that in the question. When they administered that overdose, was that on the basis that it was asked for by the patient or that it was involuntary?

**Ms O'CONNOR** - In some cases it was a response to a direct request from the patient and in other cases the patient was beyond making that request.

**Prof. TONTI-FILIPPINI** - It really worries me that there are numbers of doctors doing that. From a survey like that, I am not sure whether we can generalise to the whole population and say that therefore 36 per cent of general surgeons are -

**Ms O'CONNOR** - Certainly not. I agree with that, but there is a significant percentage.

**Prof. TONTI-FILIPPINI** - But it is a significant number and I will grant that and that really worries me. I think that it is unfortunate that there are a proportion of surgeons doing that. The heartening part of it is that it was a minority, not a majority of the respondents who said they had done that. So that is better news for me than otherwise, but it does worry me that it happens. I do not see, though, that because what in fact is a criminal offence is happening we should then change the law. If it is a bad thing to do it, changing the law because some people do it would not make anything any better.

**Ms O'CONNOR** - Professor, I am interested in the John Paul II Institute. Is that a Catholic academic institution?

**Prof. TONTI-FILIPPINI** - Yes, we are associated with the Lateran University in Rome, which is a Catholic university. We do teach a program that is advised to us from that university. I am employed here as a philosopher but obviously I am a Catholic and I do not pretend to be anything else. We teach our students a program that is approved by the Commonwealth national protocols and the Victorian standards body that accredits higher education providers, so our programs have to cover the same sort of curriculum and material that you would find elsewhere doing the same program. I teach bioethics, so if they were doing bioethics at Monash or Melbourne - and I taught at both places - I am covering the same range of material that I would cover at either of those places.

**Ms O'CONNOR** - I understand that, but would you not agree that your Catholicism has influenced your ethical approach to this issue?

**Prof. TONTI-FILIPPINI** - There's no doubt, and when you listen to me you're listening to a Catholic. All I would ask is that you evaluate what I say on the basis of what I say, not by some sort of discriminatory measure that says, 'He's a Catholic so I won't listen to him'.

**Ms O'CONNOR** - No, I am certainly not doing that.

**Prof. TONTI-FILIPPINI** - I want what I say to be evaluated for its merit. What I have said to you really comes not so much from my Catholic beliefs but just from the heart, as somebody in these circumstances hoping desperately that Tasmania won't lead the country down the track of changing the status of people like me so there we're less protected than other people in the community.

**Ms O'CONNOR** - Professor, not everyone who is suffering from a progressive or terminal illness is like you. You stated earlier, 'We want to keep on living', but do you accept that some people who are suffering intolerable pain from their own perspective don't feel the same way as you and that their feelings and rights must be respected?

**Prof. TONTI-FILIPPINI** - Yes, of course, but it has to be a balance. When you're trying to sort out legislation you have to look at a balance. If you legislate on this, all I am saying to you is that if you change our status so that our continued existence depends upon us having a strong will to live and saying that to everybody, then you have changed our context. You make it so that one of the added things in our repertoire, so to speak, is the option of dying, and that changes our relationship with those around us. We know that the carers and family around us may have in their mind the idea, 'He could end it and basically put himself out of our misery', and that changes the context. Were we to give people this option of having their lives ended, or ending their own lives with medical assistance, it changes everything for all of us and changes it dramatically. All I am asking is that you look at these things on balance and that on balance you make the decision that many other parliaments have made - that it is not safe to provide this option because it changes the context and exposes people like me, and a lot of others, to a great deal of danger.

I made a decision in December 2007 to not continue dialysis because of some difficulties I was having with coronary pain and so on. The only reason I continued was that my physician referred me to pain physicians to try to deal with that. I have kept living because of palliative care and largely I have kept living, not because I want to but because I have a 15-year-old son and older children who are still dependent on my existence. If that weren't the case, I doubt that I would continue doing what I do to try to stay alive because it is enormously difficult.

**CHAIR** - In your submission, Professor, you point out that legalised euthanasia would give those responsible for funding and resourcing palliative care services an out and that maybe there would not be a concentration on those services for our community. Yet we heard in discussion this morning that in Holland, where euthanasia has been legalised, there has been an improvement in palliative care services there.

**Prof. TONTI-FILIPPINI** - Off an extremely low base. If you compare palliative care services in the UK and the amount of funding that goes into palliative care in the UK compared to the amount of funding that goes into palliative care in Holland, there is just no comparison. That is one of the reasons, I think, why the UK has persistently refused euthanasia, because they have a much higher standard and patients have a higher achievable expectation of receiving palliative care than they would in Holland.

**CHAIR** - What observations would you make of Australia's palliative care services now?

**Prof. TONTI-FILIPPINI** - Very patchy. People in remote areas have very little access to it. Very few doctors are adequately trained although there is a program that the Commonwealth Government has offered to train GPs better in palliative care where they do placements for a time. But it is still the case that most GPs don't have adequate knowledge of pain relief. Also I know from experience that relieving pain is enormously difficult and certainly not always achievable without producing worse side effects and so on. I don't provide a romantic or rosy picture of palliative care, far from it. In Australia I think we're very under-resourced in palliative care, especially for people in remote areas, but even in the ordinary suburbs to get better palliative care for those people they have to be within about eight weeks of dying on prognosis before it is available to them. There are many people with chronic illnesses who are not going to die in the next eight weeks but who desperately need palliative care and can't get it because they don't meet the criteria.

**Ms FORREST** - Professor, I wanted to ask you your views on the difference between clinician-assisted suicide and the decision to withdraw treatment or the double effect to give additional doses of medication to relieve suffering that may hasten a person's death. It's a bit hard to know what the person actually dies from. Is it the underlying illness or the increase in medication? Also the difference there is that some people seem to think it is a minor little step while others think it is a huge chasm between the two. Would you like to describe your views on that?

**Prof. TONTI-FILIPPINI** - On the question of pain relief with side effects like respiratory side effects that hasten death, if you open up any pharmacopoeia like a MIMS, where they list drugs for doctors and give advice about them, they always have a list of indications for the drug and side effects and adverse reactions. So you have a clear idea there of the sorts of good reasons for applying a drug and then there are side effects that you have to look at and take into account; they're not what you intend to cause but they vary and if you were to intend to cause them that would be a bad thing. We are well aware of this distinction between what is intended and what is a consequence of doing something good that could also have some bad effects.

I think that is accepted in ordinary understanding that people look at those things and the issue is whether those bad side effects are chosen deliberately or whether they are disproportionate. If you are giving someone heavy doses of morphine for a mild headache it is disproportionate and the side effects are disproportionate and that would be the wrong thing to do. So there is that question that has to be answered. I don't think there is any difficulty in common understanding that there is a big difference between giving a drug in order to relieve pain or giving a drug in such doses that you will deliberately cause death. If you are trying relieve pain and the only way you can do so has a side effect where there is the risk of suppressing respiration then I think people understand that distinction. They see that that is different from just administering a fatal treatment. I think that's fairly well accepted both in medical and nursing practice and in the community because it's a common thing that we do. It's the common distinction we make. Whenever we drive a motor car we make that distinction.

The other question that you asked was about the distinction, as I understood it, between physician-assisted suicide and the withdrawing of treatment that results in death like the Mrs M case that I described of the withdrawing of a ventilator. The difference, as I understood it and in my own practice as an ethicist, is that there is a decision that is made as in the Mrs M case where she decided that this treatment was burdensome and really not for her. There are many reasons people may hold that such treatment is not for them. It may be repugnant, it may be against their religious principles or whatever, but it is for them to decide, it is not for the doctor to decide what is a reasonable treatment for that person. The doctor offers what he or she thinks is reasonable but it is up to the patient at the end of day to decide whether that treatment is overly burdensome or something like that.

I accept that there are certain circumstances where there might be a life-preserving treatment but it has too high a cost, like chemotherapy and its too many long-term side effects. As I said earlier, I've reached the point with crippling kidney disease where I thought it was too overly burdensome and painful combined with the angina that I was experiencing. I said then that I couldn't continue with this, but I see a big distinction between that and turning to my doctor and saying, 'Give me a fatal overdose'. I think those two things are very different and I think most people understand that distinction.

**Ms FORREST** - Do you think, though, when we are having the public debate about this matter and when various surveys and that sort of thing are sent out that people are confused? Do you think that the broader public clearly delineate between the withdrawal of or the non-commencement of treatment and actively giving them something to kill somebody?

**Prof. TONTI-FILIPPINI** - I think most people understand the distinction. I do think there is a fear in the community that they will be given treatments they don't want and I think that often confuses the euthanasia issue, that what in fact they want is not to be kept alive by measures that they wouldn't want applied, and I think that is very different to turning around and saying, 'Give me a fatal treatment'. I think people can see readily the distinction and I don't think it's all that confused in the community the distinction between killing somebody and withdrawing an overly burdensome treatment. I think those two things are well understood.

I mentioned in my submission that I chaired the NH&MRC inquiry into the care of people in an unresponsive or minimally-responsive state. As a committee, we produced a unanimous report and set of guidelines in which we explain this distinction we think fairly well. When I say that, obviously I had an interest in it, but what I think is important is that on that committee were a whole range of people, including the Public Advocate of Victoria and quite a lot of doctors who have been involved in making these decisions who came on to this committee with very different views and then reached a unanimous decision. I would recommend those guidelines to you for that explanation that's offered there.

**Mr GAFFNEY** - Thanks for directing us to the guidelines; I found those very helpful. My only concern is about people in rural and remote communities who do not have access to adequate medical services. Say a person knows that their time is coming, they want to die at home with their families and friends surrounding them, but they know that they're not going to get the right care at that place because of inadequate resourcing or a whole range of situations, so that person says, 'I choose to go now because I can't bear the pain and I want to go with a sense of dignity'. That has been proposed to us and it is very hard to argue about at one level other than an ethical level. Could you make a response to that comment?

**Prof. TONTI-FILIPPINI** - The straight not ethical but consequential response I would make is that if we legislated to give those people the opportunity to kill themselves because palliative care is inadequate then we've done exactly what I'm fearing - that is, that instead of properly resourcing palliative care and training local doctors to offer palliative care we have gone down the other route. I think that would be a huge mistake for a parliament to legislate to do that because a government hasn't provided adequate resources to palliative care. The answer to this is not legislation but proper resourcing of palliative care and the proper training of local GPs so that people in remote areas can know that their local GP can provide them with adequate palliative care.

**CHAIR** - Thanks, Nicholas, we're out of time. Is there anything you would like to enunciate before we move on?

**Prof. TONTI-FILIPPINI** - I am grateful for the opportunity and wish you well with what you are doing. I know how difficult it is when you get this huge raft of submissions to try to sort out. I wish you well with it and I know it's not easy.

**CHAIR** - Thanks very much for your time.

**THE DISCUSSION ENDED.**

DISCUSSION WITH **DR ROGER HUNT**, DIRECTOR, WESTERN PALLIATIVE CARE (CHRISTIANS FOR CHOICE WITH VOLUNTARY EUTHENASIA) VIA TELEPHONE LINK.

**Dr HUNT** - I am a palliative care specialist and I have been working in the field since 1984, so for a quarter of a century. During that time I have been in a position of seeing many, many people at their taut-end of their life and have been responsible for their care. So I am well aware of the different experiences that people go through at the end of their lives. I am a palliative care doctor so my role is to try to relieve discomfort, distress, pain and various symptoms as best I can.

However, it is not possible to relieve or eliminate all the suffering associated with someone who is dying. There is considerable residual suffering. Often it is not to do with physical symptoms so much as the loss of independence, the reliance on others, the sense that some people experience of being a burden on others, the thought that they are not going to get any better and that things are only going to get worse, the feeling that they have actually accomplished what they wanted to in life, lived their life and that there is not much future for them other than further deterioration and suffering. Many people, probably about 5 per cent to 10 per cent of those I see who are dying with diseases such as cancer, wish that it would hurry up and wish so strongly that they approach people around them with questions about how they can have it speeded up. It is, as I say, between 5 per cent and 10 per cent of people with a terminal illness. I come up with that figure because there have been several surveys from various parts of the world, in England and of course in the Netherlands where voluntary euthanasia is possible. About 7 per cent of cancer patients who die actually have voluntary euthanasia. In the hospice I was working in during the mid-1990s we asked the question of ourselves, the staff, once a patient had died whether that patient ever asked any of us to speed things up or did they make any comment about the duration of their dying. We found that 6 per cent of our patients who were dying in a hospice, which was providing state-of-the-art palliative care and relief of suffering and addressing all the psycho-social and other issues, were persistently and consistently requesting a staff member to hasten the dying process. There were many other patients in addition to that 6 per cent who were making comments to the effect that they wished it would hurry up but they were not making those consistent, persistent requests.

So we are talking about 5-10 per cent of people who are dying of a terminal illness, even in that population of patients who receive state-of-the-art palliative care. That is really the nub of this whole question: how do we respond to those people?

I have been of the view that for some of these patients it can seem to be a very reasonable thing to do to accede to their wishes if they are rational, not depressed, if it is consistent with long-held beliefs and there is consensus in the family that this is the right thing for this person. To deny them their dying wish, if you like, to have a peaceful end that is more or less in their control, requires some very good reasons. I am not sure that the weight of argument is on the side of denying these people their dying wish. One argument is that you have to deny these people for the benefit of some other imagined persons. As clinicians we want to do the best for each and every patient that we have before us. To look some of these people in the eye and say, 'No, we can't help you because it might mean that somebody else has their life ended prematurely' does not sound like a good argument to that patient, I am sure - that some other imagined person may be affected at another place and time when this patient is immediately in front of you and making that request.

It is of course under the current legislation possible to say to people, 'Look, I can't do this, it's against the law. I could be on a charge of murder'. We are talking of a no less serious charge than that because if I were to say that I had deliberately and intentionally hastened the dying process then I could be on a charge of murder, which is one of the worst of all crimes. To me, that is another argument for some sort of law reform here because, when you are acting compassionately and mercifully in accordance with someone's wishes, I don't see that as the worst of all crimes and yet it is treated as such in the existing framework of law. I think some reform around that is necessary from that point of view.

Being a doctor in that situation, make no mistake, there is pressure put on us. I have had numerous patients and families pressuring me to do something to help hasten that dying process, so it can be very real for doctors. You could imagine a scenario where a doctor acceded to the wishes of the patient and family and then somebody comes out of the woodwork and says, 'You've deliberately hastened that dying process', and that is passed on to officious prosecutors, who are just doing their job to uphold the law. That doctor could then be on the most serious of charges. I think there is the need for some protection of doctors, either through law reform or in some other way. If voluntary euthanasia is still considered to be wrong, so be it, but it shouldn't be as serious a charge as murder.

**Mr GAFFNEY** - It was really important for the committee to hear from Christians for Choice with Voluntary Euthanasia as a number of the submissions we have received have come from people associated with the church who obviously are not in favour of this bill. They sometimes use the statement, 'Nothing has changed since 1998', since our inquiry held a decade ago. Do you have a comment on that?

**Ms FORREST** - Except for palliative care, they say.

**Mr GAFFNEY** - Yes, except the improvement in palliative care. Do you have any thoughts on that comment about how society is changing or how we view this topic?

**Dr HUNT** - You mentioned the Christian opposition and I find that a little difficult to fathom, because I know many Christians are certainly in favour and it comes through in the public surveys that the majority of Christians are in favour of there being some law reform, upholding the principles of compassion and mercy. If you read the gospels you will understand that Jesus was on the cross for six hours - from historical accounts of crucifixion at the hands of the Romans, people were crucified and survived for three days or more usually- before he was offered sour wine. He had been offered it, too, when he was carrying the cross up the hill but said no at the time, then after he had been hanging there for six hours he said, 'Yes, give me the sour wine', and willingly drank it. He was talking and conscious, drank the wine, said he was finished, then bowed his head and gave up his spirit. That sounds very much like a case of euthanasia. I am not sure where the Christian opposition is coming from when in those accounts Jesus didn't want to be crucified any longer and wanted a quick exit. That is a conceivable reading of the gospels, but his preaching was all about compassion and mercy and helping people in need, and these suffering, dying patients are people in need.

**Mr GAFFNEY** - Thanks for that because I hadn't heard that and with over 500 submissions, I haven't had a chance to read the gospels lately.

*Laughter*.

**Dr HUNT** - If you read the account of John, it reads very much like -

**Ms FORREST** - Verse and chapter, so we don't have to take too long finding it?

**Dr HUNT** - I do not have it on the tip of my tongue, but certainly the gospel of John, if you read that, the words that he used were that, first, he drank the wine, said he was finished, bowed his head and gave up his spirit - in very quick order.

**Mr GAFFNEY** - I have one other passage for you to make comment on. In the 1998 findings in Tasmania, the committee stated:

> 'The committee recognises that in a small percentage of cases palliative care is ineffective in relieving all pain. However, whilst regrettable, this is not sufficient cause to legalise voluntary euthanasia.'

That was, to the credit of that committee, an extensive process. I think they had more than 1 100 responses to that inquiry. Could you comment on that?

**Dr HUNT** - Most people suffer when they are dying. It is not just a small handful of people who suffer. Most people suffer when they are dying and if you look at the surveys from most prestigious palliative care units in the world, patients are suffering multiple concurrent symptoms. It might some pain or nausea; fatigue and weakness are very commonly experienced and there are psychological symptoms and so forth. The palliative care communities try to say, 'We can deal with all suffering' but the evidence is there to say that's not the case, that people still suffer considerably. If you look at anybody who is dying, most people are suffering in physical, psychological or in other ways; existential suffering is so common in people who are dying. We cannot eliminate all suffering.

It used to be the rhetoric of the hospice movement that nobody needs to suffer with good palliative care. I think that is changing; I think people are being more realistic. We are getting better at what we are doing, I think. We're always learning techniques to try to relieve pain or other symptoms but we're still a very long way from achieving that ultimate goal of relieving all suffering. We haven't achieved that and it's probably unlikely we ever will. Just about everybody suffers, but of those suffering people, it is only 5 per cent to 10 per cent who are saying, 'I want an out; I don't want to be experiencing this for however long the rest of my life is going to be'. So it's a question of what we do with those people.

If you're going to deny them voluntary euthanasia you're really going to have to put up some good arguments as to why that is, and this utilitarian argument that you have to sacrifice the wishes and interests of these suffering people who want to die for the presumed benefit of some other imagined people does not hold much validity, in my view. But that's the argument that's commonly put forward, that you have to sacrifice the wishes of suffering, dying patients who want to die, but you can't help them because it might interfere with some other imagined people and that somehow doctors are going to develop a lust for killing, that euthanasia will be expanded to other categories of people, like the disabled and so forth, the slippery-slope argument. Yet when we look at experiences in the Netherlands there are not more and more people having voluntary euthanasia. In Oregon, where physician-assisted suicide is possible, there are not more and more people having physician-assisted suicide, so the evidence doesn't really support that slippery-slope type of argument that it is going to become rampant. Where are the arguments that should prohibit law reform and where are the arguments to say that doctors who do assist people in this way still have to be classed as murderers? I think there is a lot of argument to say that there needs to be some reform around this and I think the weight of argument for me is in favour of reform.

**Ms FORREST** - I have a couple of questions but I will go straight onto that issue of reform first. You made a comment about the need for reform. Have you had a chance to look at the bill that is proposed?

**Dr HUNT** - I haven't studied it closely, I must say, so I'm sorry about that.

**Ms FORREST** - I just want to ask you a couple of general questions. I am wondering if in your view this is the best way and the only way of dealing with it, or is there other law reform that could achieve the same end without going this far?

**Dr HUNT** - Presumably this is for physician assistance?

**Ms FORREST** - Yes.

**Dr HUNT** - Without administering a lethal injection?

**Ms FORREST** - No, the doctor would be required to prescribe and/or deliver.

**Dr HUNT** - Okay.

**Ms FORREST** - And stay with the patient until they have died.

**Dr HUNT** - Yes. Look, patients do want their trusted doctor to be involved in this and I guess one of the drawbacks that might have some credibility would be whether every patient will then trust that doctor. Will some patients who do not want euthanasia be able to trust their doctors if they know they have been involved in it? By and large I think people will but even now when voluntary euthanasia is not legalised here there are some patients and families who are suspicious, so that occurs now. Whether that would be any worse in the situation of having legalised voluntary euthanasia I don't know, but having been to the Netherlands and knowing that they have a very strong primary health care set-up and doctors seem to be well and truly trusted by their patients there as much as they are here, I don't know that that argument is all that strong.

The Oregon way is that the doctor just writes a prescription and the patient can take it at a time of their choosing and some patients just choose to hold onto it but are reassured that they have their way out if they choose to take it at a certain time.

**Ms FORREST** - Sorry to cut you off but I just want to head in a slightly different direction. With the legislative changes that are being made abroad and other places that effectively do the same thing, is there any capacity just to - and I say 'just to' - amend the Criminal Code to remove that element of criminality for doctors in this circumstance? That seems to be the issue for you, as I hear it.

**Dr HUNT** - Yes. That would be one way of approaching it for sure, with an amendment to the Criminal Code to say if a doctor was helping a patient in the way the patient was requesting to be helped then the doctor should not be prosecuted for murder. If it still remains a crime it could be a lesser crime or something like that. That would be one way of approaching it. I guess one of the difficulties with that is that there still need to be guidelines for the doctors.

**Ms FORREST** - I know it's not simple. I'm not suggesting it's simple, even though I said 'just'.

**Ms O'CONNOR** - And there is no protection for the sufferers, necessarily, in that.

**Ms FORREST** - I am just saying do you think that's a possibility or not?

**Dr HUNT** - I think it would be a step in the right direction but I think having safeguards and guidelines that are put down by the Parliament, a solid framework that people have to abide by, would be probably a better framework of law.

**Ms FORREST** - Thanks for that. On another point, you mentioned that about 6 per cent of the patients in your particular unit have asked for the end of their life to be sped up, for want of a better word. Do you see in your practice depression being an issue for some of those patients, and how do you deal with that?

**Dr HUNT** - There are different kinds of depression. When we talk about clinical or serious depression, that is when somebody has only negative thoughts, they might become paranoid and their whole thinking changes. The way they live changes and they lose motivation and just have no interest or enjoyment in life. Some of those patients can respond to antidepressant therapy. Probably about a quarter of our patients are on some kind of antidepressant for major depression.

A lot of people are different to that. They get sadness and a bit of a sense of hopelessness about their situation but they're not depressed in a way that they're going to respond to antidepressants. Those types of people can still get some enjoyment out of the day and can still have some interest in what is happening around them, perhaps enjoying visits and that sort of thing. They're not paranoid, they're thinking reasonably clearly, even though they might be sad, and it's natural to be sad at the thought of leaving your loved ones and concluding your life. So that kind of sadness is not what I would call depression; people can still think rationally and understand the nature and consequences of their decisions. Sadness is very common but I think people can still make rational decisions when they're sad, but if they're clinically depressed that's a different matter.

**Ms FORREST** - Just on that point, the bill has a provision in it that requires approval from their one doctor and their palliative care professional or specialist in the area of their illness, but also a consultation with a psychiatrist to ensure that they are mentally competent to make a decision. Do you see that as an important safeguard in such a process?

**Dr HUNT** - Yes. With those safeguards I think you've got it covered. If the person is seriously depressed it will be picked up by the palliative care doctors, the psychiatrist or their usual practitioner. I think having a palliative care doctor involved is a good idea as well because if the person wants out because of physical pain that is unrelenting, for example, the palliative care doctor should do anything they can offer in the way of treatments to relieve that pain.

**Ms FORREST** - As long as you can get access to one.

**Dr HUNT** - Yes, if you can get access to one. Fortunately the speciality is reasonably well developed now and most people, certainly here in Adelaide, do have access to a palliative care specialist. I know you have some very competent palliative care doctors in Hobart.

**Ms FORREST** - Only half the State lives in Hobart.

**Ms O'CONNOR** - Dr Hunt, at our last hearing we had Australian Medical Association senior representatives present evidence that the AMA is opposed in principle - and, it seemed to me, quite adamantly - to voluntary euthanasia because I think when you boiled it down the essential argument was that doctors are here to protect life, not to end it. What is your response to that?

**Dr HUNT** - Yes, I'm familiar with the AMA position; I'm on the State Council of the South Australian AMA. Doctors are involved in the termination of pregnancy and I cannot really understand why the profession would be involved in terminating life near its very beginning, life that is not necessarily suffering, as opposed to the very end of life where the person themself is saying, 'I'm going to die and I want help to die a little more quickly because I'm suffering'. To me, if you were to be making a moral stand or a stand on the basis of the medical profession about what sort of termination of life you would be involved in, it would seem peculiar that the profession has said that with termination of pregnancy we will leave it to the conscience of the individual practitioner, whereas with voluntary euthanasia, no, it is wrong for any of our profession to be involved. I find that a little bit inconsistent and disturbing.

The opinion is split about 50-50 and the AMA has taken a pretty conservative stand on this issue, mainly because the doctors opposed have very strong voices, particularly in the hierarchy of the profession. The influential people have taken a stand against any reform but there is a case, with half the doctors saying they think reform should be possible and should be undertaken, the AMA should take a neutral stand. I presented that argument when they were reviewing the end-of-life care position. Unfortunately, from my point of view, the AMA softened its stance compared with the previous position statements. It certainly took a softer stance but yet still adopted a polarised position against voluntary euthanasia rather than moving to a neutral position and saying that it should be up to the conscience of the individual practitioner.

The medical profession in some other countries has of course looked at this issue. In the Netherlands, the Dutch doctors were some of the first movers in this area and that led to changes through the criminal code and then through their statute law. In Britain, the BMA - British Medical Association - has looked at this and just in recent years they changed their position to one of neutrality from opposition, but then went from neutrality back to opposition when the debate went on further.

The medical profession here and in other parts of the world is a bit split on this. You can appreciate some of the arguments that are put forward, that argument that doctors are there to preserve life. Being a palliative care doctor, of course I will preserve life if I can and if it is helpful to people, but I also see situations where ongoing life is an incredible burden to the person who is close to dying and is suffering. I can see that it may be kind to do as vets do for pets in their care. This is a difficult issue for the medical profession and I think over time it is gradually changing. It is a difficult issue for parliamentarians who try to reflect the wishes of the community yet want to also provide responsible leadership

**Ms O'CONNOR** - A case has been put to us by the AMA and also an ethicist this morning that changing the law to legalise doctors providing assistance to the terminally ill places a terrible burden on the medical profession and a burden on doctors to have to make that choice to be in a position where they can provide that assistance. What is your response to that?

**Dr HUNT** - I think it does provide them with an added responsibility, but not all doctors are going to be involved in this, just as not all doctors are involved in the termination of pregnancy. It is a very small section of the broad church of the profession. There will be some doctors who are willing to be involved in this and it will weigh heavily on those doctors. We are paid well to take some fairly heavy decisions in all different aspects of the profession. We carry out responsibilities as to whether to operate or not, whether to cut a person open or to use our knowledge and skills in all sorts of different ways to help people. The bottom line for me is that we are there to satisfy the health care needs and wishes of our patients. There is a small group of patients who have the desire and the need for voluntary euthanasia. Do we turn our backs on those people when they are looking at the profession to help them? It will weigh heavily on those doctors who are willing to help those patients, but I think that is a part of it. These decisions can't be taken lightly and I don't believe that responsible doctors are going to take this decision lightly. It will be a burden but I think it is one we need to address for the benefit of our patients.

**CHAIR** - Doctor, thanks very much.

**<u>THE DISCUSSION CONCLUDED</u>**

DISCUSSION WITH **Mr MARSHALL PERRON** VIA TELEPHONE LINK.

**Mr PERRON** - I will spare the committee repetitive arguments in support of legalising voluntary euthanasia and concentrate on what needs to be done to advance the cause. The Northern Territory legislation was based on a fairly simple principle: if there are terminally ill patients who wish to end their suffering by accelerating inevitable death, and there are sympathetic doctors who are willing to help them die with dignity, then the law should not forbid it. That was the basic principle that I and my colleagues held to throughout the Northern Territory debate. The Northern Territory legislation was, in fact, quite similar to the proposed private member's bill that is the subject of the committee's inquiry.

The fact that a very few people die in horrific circumstances unable to be helped by palliative care is undisputed. The committee has heard from a number of witnesses and, of course, previous inquiries, including the previous Tasmanian inquiry, all concluded that there were a very small number of people who could not be assisted with palliative care, even optimal palliative care. That is one undisputed matter.

The second one is that the doctrine of double effect is practised daily probably all over Australia in institutions where people die. Double effect is in effect slow euthanasia, usually without patient consent, without safeguards, witnesses or transparency. The committee has been told that double effect is good palliative care. Double effect in fact gives the doctor full control of events and the patient virtually none at all.

Since the last Tasmanian inquiry, several places around the world have legalised the assisted dying and the predicted collapse of society has not occurred. The 80 per cent of Australians who support voluntary euthanasia are not asking parliaments to lead on this issue any longer. They were once but today they are asking our politicians in fact to catch up.

Politicians are paid to study concerns within our society and work to find solutions to those problems. So far on this issue most Australian politicians have ducked and weaved and said that it is all too hard. Past excuses like palliative care has the answers or the vulnerable will be at risk or the chilling religious view that we should all bear the suffering because it is God's will, just do not wash anymore.

The often repeated but never substantiated statement that no adequate safeguards can be devised to control voluntary euthanasia is nonsense. We need more politicians committed to reducing the senseless and needless suffering of a very few to work together to devise the appropriate mix of safeguards rather than simply accepting that it is a stumbling block that cannot be surmounted. This task of examining the safeguards necessary to bring in appropriate and responsible voluntary euthanasia legislation can only be done by people who accept that there is such a thing as rational suicide. Many of the submissions made to the committee are certainly made by people cannot accept, under any circumstances, that an individual can rationally take their own life. What we have yet to see, following the committee's report, is if there are many such people in the Tasmanian parliament.

**CHAIR** - Marshall, when the terminally ill legislation of the Northern Territory was overturned, what was your reaction and perhaps the community's reaction to that?

**Mr PERRON** - I was fairly devastated for a couple of reasons, not simply the fact that it was legislation that I clearly believed in, having been its architect. There were two challenges to the legislation. The first one was a legal challenge which went to the High Court in Australia. The second one was an appeal to the Prime Minister, then Paul Keating, to use an executive power that the Federal Government has to get the Governor-General to withdraw assent from any legislation passed in the Northern Territory. An appeal was made to the Prime Minister, who examined the issue at the time and ruled that that would be an unwarranted interference in Northern Territory affairs and that this was a matter to be solely left to Territorians. He was doing that on the basis that if Territorians felt it was a bad law then of course it would be amended or repealed, and it was not for Federal Parliament to intervene. However, other forces some months later determined that the private member's bill was an appropriate course for the Federal Parliament to take. Notwithstanding an extraordinary reaction by Australians against such a move, the legislation was successful and the Northern Territory not only had the legislation overturned, but the power to handle such legislation in the future was withdrawn from not only the Northern Territory but also the ACT.

**CHAIR** - What was your sense of the reaction from the community, Marshall, at that time?

**Mr PERRON** - The community reaction was one of outrage. It was reflected in talk-back radio and letters to newspapers and the like across the country. It was a reaction which probably would match any other broad community reaction on any issue in Australia's history. I say that because it is one of those issues that rate an 80 per cent support base in the community, as the committee has heard. I cannot think of another issue, perhaps with the possibility of reducing taxes or whatever, that would rate 80 per cent community support.

Most controversial issues, of course, rate nearer 50/50 support or opposition in the community. But consistent polls since about 1946 have shown an increasing support for the right for voluntary euthanasia among Australian adults.

**Ms O'CONNOR** - With respect, you are an old political hand so I am interested in your take on this. Why do you think there is such a schism between the community's wishes, the 80 or 70 per cent that responded to poll down here, and the political framework?

**Mr PERRON** - I think it is because politicians are scared of the minority view being a more powerfully felt view than the 80 per cent who support it. Let me just take one step back. I believe that parliament is, by and large, representative of the community. I say representative because politicians in Australian come from all walks of life. If that is true then one can assume that if a genuine poll was taken of their views then you would have to rate somewhere between 60 per cent to 80 per cent support for voluntary euthanasia among politicians. I think we can take that as fact. However, very few politicians are prepared to stand up and show their colours on this issue because they hold their seats by relatively small margins, and in some cases minute margins, and to have a group become very active in a political campaign, able possibly to influence a few percentage points in the poll, scares the life out of many politicians. They know that church groups can organise their flock far more efficiently than voluntary euthanasia organisations.

So what we have is an 80 per cent support for voluntary euthanasia in the community which you might call soft support.  It is support anyway; there is not question about the support.  But if you ask someone to walk a kilometre on the issue they would probably say, 'Look, I am busy today'.  The minority 12 per cent who oppose voluntary euthanasia - the balance of course are the undecided - almost exclusively are religious-based-faith opponents to voluntary euthanasia.  They feel so powerfully about the issue that they will walk a kilometre and do something about it and possibly change their vote and that is what terrifies politicians.

**Ms O'CONNOR** - Thank you, Marshall.  We had in here this morning a leading ethicist in Tasmania who was saying - and this is the language that he used - 'If we allow doctors to kill people, what does that act imply about the sort of community we are?'.  So, to soften the language a bit, if voluntary euthanasia were passed in Tasmania, what do you think it would imply about the sort of community we are?

**Mr PERRON** - I think it would imply that it was a progressive and humane society which would in fact lead the rest of Australia.

I believe quite firmly that the advent of voluntary euthanasia or legally-assisted dying in western society is absolutely inevitable, particularly with advances in medicine being such that people are now living longer and longer.  The medicines are so good now at keeping an ever-degenerating body alive that more and more decisions are having to be made to allow people to die.  This is obviously the switching off of life-support machines and withholding of antibiotics et cetera.  The numbers of people who will die when someone makes a decision for them will escalate rapidly with the ageing population, with more and more deaths from the slow, degenerative diseases that we face today that 50 years ago we did not even live long enough to get.

I believe that society is going to go down this path, as has happened elsewhere in the world, and in probably 30 years' time people will look back and say how barbaric it was that Australia allowed people to take their own lives by suicide through starvation and sat back and said, 'We'll sedate you and watch you die over 12 or 14 days but we won't allow you sedation of a level that will kill you at your request quickly and peacefully'.  It is just barbaric and some members of our society are having trouble coming to grips with that.  I believe that our politicians are paid to address these issues and not to look at how things can't be done but to examine each of the safeguards in some detail and put together a responsible mix that society is happy with, and then monitor it very closely.

**Ms O'CONNOR** - Thank you, Marshall.

**Mr GAFFNEY** - A number of the submissions we have received mention the failure of the NT legislation or its overturn, but they also mention individual cases in the NT and say this proves that it wasn't in fact good legislation.  I am wondering whether you would like to make comment on those individual cases overall.  How do you respond to those people?

**Mr PERRON** - Yes, I would, and thank you for that question; I was hoping it would come up. What is normally quoted is a document called 'Seven Deaths in Darwin' which was printed, I think, in the *Lancet* following an examination by three gentlemen, one of whom was Dr Nitschke who was obviously very involved in all of those cases in Darwin and who I understand will be giving evidence to your committee later on.

**CHAIR** - This afternoon.

**Mr PERRON** - My examination of this issue has been quite thorough because I was pretty appalled when that report was first released saying that all the people who were assisted were assisted wrongly. I was just appalled because I know the families of a number of those people and am aware of the suffering that was involved.

So with the exception of Dr Nitschke, the other two authors of the report were clearly of the view that, irrespective of the circumstances, if an individual wants to die they are in no mental state to make a decision about dying. Now this is a classic catch-22 view that is often put by opponents to euthanasia: if you think you want to die then that clearly demonstrates that you are depressed to a point where you shouldn't make a decision about dying, and the authors of that report were very clearly of that view. In my view they had set out to destroy the legislation or do their best to do so, and I think Dr Nitschke, who was involved in the report, was conned. It would be interesting to know whether he would accept that view.

I believe that it was a pathetic, patronising attitude to take and that a competent adult has every right to make his or her own decision about death and dying. As I say, knowing personally two of the families of two of those people who died in the Northern Territory using the legislation, they equally were simply appalled to be told in this report about their loved one who had suffered - and the detail of the suffering in 'Seven Deaths in Darwin' was just heart-wrenching - that, 'These people simply needed more love, care and attention and some treatment for depression and they would have been okay'. That is simply breathtaking, in my view.

**Mr GAFFNEY** - That is two of them - can you give us any others you know of personally as well?

**Mr PERRON** - Sorry, I knew three of the people. There was one whose name has never been released - and Dr Nitschke would know that - the others were made public at the time. So there were three that I know of, all of whom are advocates of voluntary euthanasia today. Those family members have not changed their views; in fact they have supported that other people should have those similar rights.

**Mr GAFFNEY** - In the NT legislation, was there an examination by a psychiatrist? In the Tasmanian legislation that is one of the safeguards. If there wasn't in the Northern Territory, do you believe the Tasmanian proposal is a good one?

**Mr PERRON** - Sorry, if there was or wasn't in the Northern Territory?

**Mr GAFFNEY** - Was there psychiatric assessment in the Northern Territory legislation?

**Mr PERRON** - Let me explain. Initially, no. My private member's bill had no requirement for a compulsory examination by a psychiatrist. I strongly believe to this day that it is completely unnecessary and that a medical doctor treating terminally-ill people is perfectly capable of making an assessment as to whether an individual is depressed to the point that they are clinically depressed and would benefit from treatment. We had the requirement, I think, that a psychologist was involved. However, after I retired from Parliament after the legislation passed but was not yet commenced, it was amended and a psychiatrist was put in there as a compulsory part of the safeguard process. I notice that the Tasmanian legislation has a similar provision. It does not make the legislation unworkable; I just think it is an unnecessary hoop the patient has to go through. However, if Parliament dictates that it is a requirement that it wishes prior to supporting such legislation, politics is also the art of compromise and for that reason I would support it going forward as it is in the draft bill in Tasmania.

**Ms FORREST** - On that point, your flow chart says that the psychiatrist is only required to confirm the patient is not suffering from treatable clinical depression, whereas in the Tasmanian legislation the psychiatrist is required to determine that the patient is mentally competent. Do you think that's going a bit too far?

**Mr PERRON** - No, probably not. To determine competency I don't think is hugely difficult for a qualified person. I believe an MD would be perfectly comfortable with it. What we must understand is that people can do all sorts of things with their lives that you and I might strongly disagree with. In fact, just look at society. People do some very strange things. They might give away all their money to the local cats' home, they might make a decision to withdraw life-saving treatment that would extend their lives. All of these decisions could be made and you might say, 'I wouldn't have made that decision. That's pretty serious stuff and a very strange decision'.

**Ms FORREST** - With all due respect, on that point -

**Mr PERRON** - They are competent to do it, that's what I'm saying.

**Ms FORREST** - Yes, but the point is that for those people, if someone has concerns about their competency, they will then go to the Guardianship and Administration Board for an order. People with bipolar disorder, for example, who are going through a particular bad patch may need to be appointed a guardian for those short periods of time when they are making inappropriate decisions, as you just described. Do you think a psychiatrist needs to be the person, and not just a doctor, to determine that or is it too restrictive?

**Mr PERRON** - I would be happy to leave the whole issue to a doctor and take the psychiatrist out of the picture altogether, personally.

**Mrs BUTLER** - Do you accept that some doctors get awfully emotionally involved with long-term patients?

**Mr PERRON** - I do not understand what that means. It is good to have a doctor emotionally involved with a patient, I would hope.

**Mrs BUTLER** - As a practising social worker I have been asked to go and tell someone that they are about to die because a specialist who had been seeing someone for 26 years did not feel that he was able to. That is the sort of level that I am talking about.

**Mr PERRON** - Yes. I am not sure I can add further to it. Under any legislation, of course, if someone is deemed to be incompetent and requires to be, as it were, locked up for their own safety or other persons' safety, well those laws still apply in any circumstances, quite separate to this legislation.

**Ms FORREST** - There has been evidence in our submissions that when you brought this bill into Parliament you were unaware of what palliative care was or involved; I would like a bit more background to that. Also, some issues have been raised about the Aboriginal people in the Northern Territory being fearful of going to hospitals or doctors as a result of the passage of the legislation.

**Mr PERRON** - On palliative care, when I was asked to give a complete description of what palliative care covers I was found wanting in my knowledge and I acknowledge that. The issue is, of course, that we did have a very small home-based palliative care service available in the Northern Territory at that time which was, as a result of this debate, including my lack of knowledge, dramatically ramped up. It was pretty big political news at the time, meant that the whole of the Northern Territory community was very quickly educated about what palliative care really means and the extent that we should fund it in our community. I am pleased to say that the legislation in the Northern Territory, which was perhaps short-lived, has left a legacy of a far more extensive and thorough palliative care service, because all voluntary euthanasia advocates, including myself, are strong supporters of palliative care. We do not believe that anybody should seek voluntary euthanasia because they cannot access good palliative care. However, in saying that we also have to acknowledge that there are people who are not enamoured with palliative care and would prefer to handle their medical issues themselves, as is their right. We do not want a situation where palliative care is somehow a compulsory sort of stay for any terminally ill individual. If someone determines that they do not want treatment for their cancer, for example, they do not want to continue with any of the palliative options and they would prefer the matter to take its course, then that is their choice and we should support that.

On the second issue of Aborigines, that was a disgraceful event in the Northern Territory where we had opponents to voluntary euthanasia spreading the word in outback tribal Aboriginal areas that this legislation meant that if you went to hospital the doctors could put the old people down. Of course it was alleged that there was a great fear as a result of that among Aborigines seeking medical attention and particularly being flown to Darwin for medical help. That action by some unscrupulous people was roundly condemned, I am pleased to say, in Parliament by opponents of my legislation who felt that the tactics were below the belt. At a subsequent Federal Senate inquiry, the Aboriginal representatives who went before that inquiry into the Northern Territory legislation acknowledged under questioning that the statements by the Northern Territory Health Service that there had been no evidence of Aborigines refusing to seek assistance as a result of these rumours was correct. In other words, some of the ammunition that they were firing did not reach its target.

At the end of the day, if a poll were done amongst Aboriginal communities there would probably be a strong anti-voluntary euthanasia view. I accept that. There would probably be a strong view against harvesting organs or prostitution or abortion and other things amongst Aboriginal communities too, but that does not stop us having laws on those issues. Of course, voluntary euthanasia is a law that only affects those people who opt for it. It does not affect others.

This legislation got up by one vote in the Northern Territory Parliament. One vote was from a full-blood Aboriginal member of parliament who came from an Aboriginal electorate - Wesley Lanhupuy. The electorate itself strongly opposed voluntary euthanasia because of its high Aboriginal content but this full-blood Aboriginal member of Parliament, now deceased sadly, made a most brilliant speech in Parliament as to why he was supporting the legislation. It is on Northern Territory *Hansard* if you care to refer to it. I thought that put the Aboriginal counter-view to the view that this legislation should not proceed because Aborigines did not like it.

**CHAIR** - Marshall, thanks very much.

**THE DISCUSSION CONCLUDED.**

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

**CHAIR** - Thanks very much, Professor, for joining us here today.

**Prof. OTLOWSKI -** I became engaged with this issue of euthanasia as part of my PhD studies which I commenced in the late 1980s, so it is quite some time ago. I acknowledge that I came to it perhaps with a fairly idealistic belief in a person's autonomy and self-determination. I am not saying that perspective is not important, indeed I still think it is very important, but since that time, particularly through the 1990s, emerging clinical data has convinced me that there are even more compelling reasons why we need to legislate in this area in order to provide safeguards to patients and also ensure that the conduct of doctors in providing assistance can be appropriately scrutinised and regulated and, where appropriate, supported - provided safeguards are met. With the current practice that occurs in a hidden and unregulated manner, there are greater risks for patients and for doctors.

What I am suggesting is that in evaluating the desirability or otherwise of enacting this legislation, we are not facing a choice of whether assistance in dying in Tasmania should commence because there is incontrovertible evidence that it is already occurring. Rather, I would suggest, the question is whether we continue to turn a blind eye to the practice and pretend that having prohibitions on our statute books is effective to protect patients from unwanted or inappropriate intervention or, alternatively, to be more honest and open about what is happening. So, recognise that these activities occur and endeavour to regulate the area and make it as safe as possible. For example, limit it to circumstances where palliative care has been attempted but found wanting, or limit it to people who are at the terminal stage of their life and set some restrictions around it.

The reason I premised the question in that way is based on some of the empirical data that I have sought to put before the committee in my submission. Firstly, there is evidence that patients in a terminal condition do make requests for voluntary euthanasia. I am not just talking about a single survey. I am talking about often using the same methodology. There is some comparability also with data from the Netherlands. Questions of doctors about whether they have received such requests have been based on samples in the thousands and I understand they have been published in reputable journals. I understand that to be reliable information and approximately half of the doctors so surveyed have indicated that they have received such a request at some stage.

**CHAIR** - Dr Roger Hunt this morning submitted that between 5 per cent and 10 per cent of people in palliative care would make that request.

**Prof. OTLOWSKI** - You will be hearing different things from different people. This was a survey through a questionnaire where people could reply anonymously. He is speaking for the palliative setting. I would have expected it to be higher in that setting. All I can do is report the data as I see it and obviously you will have to weigh up whether that data conflicts with other data.

**Ms O'CONNOR** - His words were, 'Persistently and consistently requesting assistance to die'.

**Prof. OTLOWSKI** - So it is not necessarily inconsistent, then, in that case. This is just indicating that these doctors, at some time in their career, have received a request and it may be that they have received more than one request. So perhaps those things can sit reasonably comfortably together.

**Ms FORREST** - Did they say that was in situations where they were treating someone with a terminal illness or is that more broadly, because people go along who are suicidal? If they are lucky they go to their GP and have a chat. Women in labour ask to die quite frequently, but we do not take that very seriously. We take it seriously that they are in pain but we do not take seriously their request to die.

**Prof. OTLOWSKI** - We would have to look at the survey methodology and the cohort of doctors they were recruiting. It was not necessarily people limited to palliative care circumstances. I think from this we can gather that at least some patients make that request. It is hard to put figures on it but certainly some patients are making such requests. Further, there is evidence that some doctors are responding to these requests. Again, there may be debate about the figures, but at least two or three Australian surveys - and there is some validation of these results through similar methodology undertaken in the UK - suggest that 28 per cent of respondent doctors, and it goes up to in excess of 30 to 35 per cent, have indicated that they have responded to such a request at some stage. It may have only been once; it may have been on more than one occasion. It is enough to demonstrate that some of these requests are responded to by medical practitioners. I would be very surprised if anyone can assert that this does not sometimes occur.

Because of the acceptance of palliation and administration of pain relief, even though a doctor knows that it will cause death, that has become a legal exception to the normal rules of murder for intentionally or knowingly causing death. So case law has created an exception. It is also pretty well known that sometimes, under the guise of legitimate pain relief, euthanasia will occur anyway. There is also a practice, sometimes referred to as pharmacological oblivion, where people can be rendered permanently unconscious, ostensibly for pain relief but it becomes very close to a slow euthanasia anyway because you know they're not going to come out of that unconsciousness. They may be given a drip for hydration or whatever but it is not far removed from a more direct form of assistance. That is seen as acceptable and lawful and yet euthanasia is not so I just mention that as well.

My main concerns arise from what I see as the problems stemming from an illegal and covert practice. It is often said that the law can be brought into disrepute but I think if we go to the essence of what is being undertaken here, the fact that doctors work secretly, perhaps in fear, I'm not suggesting they have bad motives; I think they are acting sympathetically in what they see as the best interests of their patients but there is minimal, probably negligible, opportunity for consultation amongst peers in an environment where we're talking about a practice which is unlawful. I would suggest that this has implications on the quality of medical decision-making in this area.

Furthermore, and somewhat related to this, is the fact that a practice that is unregulated and covert has the real potential to threaten and undermine the rights of individual patients. There is more risk of euthanasia occurring in inappropriate circumstances if we are talking about an unregulated practice. Again I draw on some of the empirical data because in some of the surveys doctors were asked whether they had always received an unequivocal or unambiguous request for assistance before they had acted to actively terminate the life of a patient. In some cases, as many as one in five doctors who had acknowledged their involvement in direct assistance had said they had not received an unambiguous, unequivocal request but had nevertheless acted.

Australia, including Tasmania, is a country where euthanasia is prohibited, and if we compare this data - and there is some comparable data because researchers were attempting to ask similar questions from around the mid-1990s - between Australia and the Netherlands, where they had already de facto legalised it and it then became implemented through legislation, what that suggests is that where there was not an equivocal request, euthanasia in those circumstances in Australia was five times more common in a percentage sense than in the Netherlands, where the practice was open and regulated. Yet they had similar data also for voluntary euthanasia where it was not an explicit request and those figures where actually comparable for the two countries. This is of course despite having prohibition in this country.

That suggests that euthanasia is occurring in Australia despite the prohibition against it. In fact it is probably occurring more often than not in a manner that is other than a really explicit, clear request that is discussed and understood. I think the reason for this, if we are to speculate, is that, because it is unlawful, doctors are probably fearful of engaging and discussing it and when patients are declining and obviously suffering it is more likely that they will take the decision on themselves.

I do not want to be judgmental of the medical profession about this. As I said, I am not suggesting there is bad motive in the sense that there is the malevolence we would normally expect when we talk of murder, but I don't think that is the best manner in which assistance to die can occur. Indeed, there are instruments seeking to protect the patients' right to life, there is the International Covenant on Civil and Political Rights, to which Australia is a signatory, which has a right to life.

I think that any intervention other than that which is clearly based on the patient's request is not appropriate and for that reason I think we need to do more to ensure we can bring the practice into the open, create a lawful pathway for doctors to perform it, have the opportunity to scrutinise and regulate and, where doctors want to avail themselves of the legal immunity, that they are then accountable to do so.

You may be wondering that if there seems to be some practice of euthanasia why we have not had prosecutions of doctors in this country. To some extent I think that tells us about the manner in which this sort of conduct is viewed by society; that it is in fact not generally seen as criminal conduct warranting punishment in the same way other taking of life or murder would be, or assisting suicide. I suggest that there is a distinct reluctance on the part of law enforcement authorities to become involved in the investigation and prosecution of such cases and, of course, we know there is a public-interest component to decisions about whether to prosecute.

There are some good examples of this because some doctors have been very open about their activities almost to challenge the authorities and law reform bodies. By illustration, I'd like to draw on what happened some years ago when an open letter was published in the *Age* that was written to the then Premier of Victoria, Jeff Kennett, explaining that they acknowledged that they'd broken the law by assisting patients to die and either calling for them to be prosecuted or for the law to be changed. That did not go anywhere in terms of prosecutions, despite open and public admissions, and I would suggest that even if there was to be a prosecution there would be every likelihood that a doctor would be dealt with leniently provided a bona fide motive could be established.

We virtually have no Australian precedent. I do not know of any proper euthanasia cases where the patient has requested and the doctor has assisted, but certainly from other jurisdictions - the UK, Canada and the United States - there have been some precedents where the doctors have either been acquitted, sometimes on the most spurious technical grounds that it could not have caused death, even though the doctor had written in the notes about injecting air into the patient's veins and then hadn't denied it at trial, but the jury acquitted on the basis that it was plausible that perhaps the patient would have died from other causes rather than from this intervention, even though the doctor had entered in the notes, 'Patient expired 10 minutes after this commenced'. This is an example of the justice system in operation, and in this case of a jury not wanting to find a doctor criminally responsible for this sort of conduct.

There have been other incidences of leniency if there has been a finding of guilty so, strictly speaking, even though motive is irrelevant to the crime of murder, in practice it seems it is crucial to how these cases are dealt with if they do come before the criminal justice system.

It might be tempting to say that some people have access to euthanasia, some doctors are assisting and are not being punished, and perhaps that is enough of a solution. 'What's the problem?' in other words, but I would argue that it is not a satisfactory situation, firstly from the perspective of the patients and their protection because of the information presented concerning some instances of it being other than at the explicit request of a patient, but also I think we have to look at it from the point of view of doctors and we really have to question whether it is fair that doctors are faced with this sort of serious criminal liability if they want to act to assist their patients.

The other reality is that, whilst the majority of cases have dealt with doctors overseas in the criminal justice system very leniently, this can't be reckoned on as a certainty. There was a recent case in the UK of a Dr Cox, who was convicted of attempted murder - it could not be established because the body had already been cremated - based on various drugs he had administered and it was then reported. He was given a suspended prison sentence, which is a serious outcome in a sense, but he was allowed to walk free and the medical tribunal allowed him to continue to practise and obviously continued to regard him in high esteem as a professional consultant who hadn't actually done anything wrong. What I am suggesting is that in reality, the current criminal law prohibitions do not reflect the contemporary view of reprehensibility and we need to close this gap, I would suggest, between the overt culture, what the law expresses, and what actually happens in practice, and then seize the opportunity to try to regulate and make things safer.

From my perspective at least, that for me is the most compelling reason we need to make a change.  There are the other arguments that I have addressed in my submission to do with patients' rights of self-determination and autonomy.  I don't want to go into that beyond what I have said there other than to say that any so-called right to self-determination does not translate into a right to euthanasia.  Obviously we have to respect the freedom and the choice of doctors involved here as well.  The best it can be translated into is an opportunity to make the request and have that request considered on its merits and a determination made as to whether a person is eligible for euthanasia.

As for arguments against, I do not think it's for me to raise them and then counter them.  I have tried to do that a little bit in my submission.  What I would simply say about that is that there may be some valid concerns but I think they can all be adequately dealt with through the imposition of appropriate safeguards.  I would just refer to John Stuart Mill's harm principle or theory as to when criminal law intervention is appropriate and that there really needs to be a compelling social interest to ask the question, if we are talking about terminally-ill patients, what the harm is in terms of doctors providing this assistance if the patient has requested it and where there is already an inevitable death.

The other point I wanted to mention concerns public opinion data and the fact that there is seemingly strong community support for reform.  Clearly one cannot act on opinion polls just as a knee-jerk reaction.  I totally accept that that information may possibly be misinformed or for other reasons, but if in other respects a strong case for reform can be made out, having regard also to what the consequences of legalisation are, then I think there is room to look at what the community is saying through these opinion polls.  I am sure you have heard evidence about this already, but it is often a high percentage in favour.  I understand that the poll on this particular bill indicated in excess of 70 per cent supporting it, so I think you need to be mindful of this.  Public opinion does reflect the prevailing morality and the needs of the community and ultimately the law must serve those needs.

In terms of the doctors' perspective on this, I know you would have heard evidence already from various doctors.  I am sure they've given strong reasons as to why they are personally opposed to legalisation.  I suspect in many instances that might be based on their own religious viewpoint.  What I would suggest is that individuals do not necessarily represent the medical profession.  Interestingly, medical organisations remain opposed to legalisation but there is empirical data to show that when doctors are surveyed, perhaps less than the public opinion data but nevertheless the majority of them are supportive of change, and some of those doctors have indicated that if there was a lawful avenue they would avail themselves of it.

I think it's also useful to draw on the experience from other jurisdictions where there has been legalisation to counter concerns about the impact on the medical profession, because there is no evidence from those jurisdictions to suggest a deterioration in the trust or quality of the doctor-patient relationship.  Indeed, I think the fact that we have some models to draw on where there has been legislation implemented, and particularly in the Netherlands where they have the most longstanding experience, shows that it can be done but above all, I think we can learn from this experience by seeing the advantage of bringing the practice into the open.

Experts in the Netherlands believe that now the great majority of cases that are occurring in practice are being notified to the authorities, there is a process of review of the paperwork and only a tiny proportion are taken further. In recent years they have had no criminal prosecutions but some cases have gone to the medical disciplinary bodies if they feel that there have been some gaps in the administration. I think this is really relevant evidence to this committee because it shows that if doctors are given a lawful approach to adopt, that can provide what the patient seeks, but also provide them with a legal immunity, they are likely to avail themselves of it.

In terms of the bill's particular provisions, I know you have had a submission also from the Law Society. I do not propose to get into the minutiae of it although I am happy to try to field questions as appropriate. I would be more concerned to look at the overview and the types of safeguards that the bill contains. By and large, it is a cautious approach. Its emphasis is on voluntariness, ensuring that it is limited in terms of who it can be used by through the requirement of the terminal condition, and the things to do with diagnosis of that condition, and also the patient's mental competence through psychiatric assessment. I think all those things are important, as is the requirement about at least attempting palliative care. So, in those broad terms, I do believe that it has most of the essentials in place.

It is my view that, if this legislation were to be enacted, we would have a far greater opportunity to regulate the practice and to create safeguards for both patients and doctors than if we allow the current unregulated practice to continue. So what we need is an environment in which decisions can be made openly and subject to scrutiny, and where doctors who want to have benefit of immunity will be held accountable for their decision-making. This is going to be the only way we can make it safely available and avoid some of the anomalies and inconsistencies in the law.

There is no evidence to suggest that a lot of people would avail themselves of this option. For many, it would be more the psychological security, the knowledge and almost self-empowerment that if they needed to, as a last resort, then they could. Of course, every effort should be made to avoid the necessity for that intervention and that is what the palliative care provisions in the bill are seeking to ensure.

I know that often this issue becomes sensationalised or perhaps there are scare tactics in the media. But it is really important, as we proceed, that there is objective and dispassionate consideration of these issues, regardless of one's own moral or religious viewpoints. I am nominally Roman Catholic but I put religion out of my mind on this issue. There may be good justifications for legalisation or at least decriminalisation in order to maximise protection of patients. I do appreciate that this is a difficult issue and that people feel uncomfortable about the prospect of legalising euthanasia. Above all, we must not ignore the reality that it is already happening, albeit dangerously, and I think it really does call for strong leadership on the issue.

**Ms O'CONNOR** - You cite in your submission the *Medical Journal of Australia* survey of doctors which found that 36 per cent had administered medication, knowing that it would alleviate suffering but with the intent, essentially, of ending the patient's life. In your view, is that manslaughter, attempted murder or murder?

**Prof. OTLOWSKI** - Technically it would qualify as murder because there is the intention of bringing death about. There is this grey zone about medication and pain relief. That exception is limited to circumstances where the intention is not to bring about death but the doctor knows that it can be a consequence. I think that data is different to that because it included an intention to end the life, but it was also given for avoiding stress and alleviating suffering and so on. But the intention was there, so technically that would suffice as murder. How it would be dealt with is another matter because of the leniency and sympathy in the criminal justice system. But I have no doubt that in terms of the mens rea for murder that it would be enough.

**Ms O'CONNOR** - How do you respond to the position put by the AMA, which is essentially that a doctor's role is protect life, not to end it? That seemed to me to be the foundation of their objection to voluntary euthanasia.

**Prof. OTLOWSKI** - I would always accept that is the primary role but we have to look at the situation in context. We are talking about patients who are already at the end of life. There is no hope of restoring them to health. They are in a terminal phase. It is not as if we are now asking the medical profession to begin to become involved. I come back to the empirical data that it is happening anyway, so what is their response if there is data that suggests some of their members are already acting in this way? I would turn the question back on its head. Further, there are other justifications for saying that a compassionate response where there are no other options does not detract from the medical role. One could look to some of the work done in the Netherlands about the quality of doctor-patient relationships. If anything one could say that it can actually work to strengthen relationships in terms of that deep trust and understanding and a sense that one will not be deserted in the time of need. Merely that knowledge, even though it is often not necessary to rely on a request for implementation, is going to be of great psychological benefit to patients who are in distress.

**Ms O'CONNOR** - We have had a number of submitters citing the previous parliamentary inquiry in 1998 and saying nothing has changed since then, therefore where is the argument for changing the law. As a person who has spent a lot of time looking at these issues over an extended period of time, in your view what has changed since that inquiry recommended against a change of the law?

**Prof. OTLOWSKI** - Not necessarily a lot. There was already data emerging then about some of the concerns and the risk factors. If we look at what happens in practice there have been numerous bills over a long period. It is a difficult issue and often the hard matters are dodged. We fail as a society to take the opportunity to deal with this more proactively. Despite the public support and all the factors that point to the logic of change, I accept that there is a real aversion to be moving into this territory.

**Ms O'CONNOR** - Does that come from fear?

**Prof. OTLOWSKI** - I think religious belief and concerns about offending people in the community is a huge aspect in this. It often becomes the elephant in the room, even if people are not talking about it. There is also the fact that there are not many precedents. We had this experience in the Northern Territory. Almost annually there would be a number of bills before the parliaments and almost invariably they are unsuccessful. There is a concern that this is outrageous, this is radical and extreme, but really by taking that kind of approach we are turning a blind eye to the problem. I do not think ignoring it makes things better. My own personal view would be to try to bring things into the open for the benefit of the stakeholders, the patients and the doctors. Give them an opportunity to deal with this in a safer way, a more certain way, a way that can be measured and quantified and where we are in a better position to understand what actually is occurring, in what circumstances, and to put in protections rather than have it occur in a manner that we really do not know a lot about.

**Ms FORREST** - You have said a lot of things about the need to acknowledge what is happening and the need to put a framework around that. Do you think this bill does that and meets all those areas? For example, the definition of terminal illness is 'an illness which, in reasonable medical judgment, will in the normal course, without the application of extraordinary measures or of treatment unacceptable to the sufferer, result in the death of the sufferer'. When you look at that in a broad context and how it relates to the latter parts of the bill, someone with diabetes, for example, if they do not take their insulin, will die. There is nothing surer than that. It might not happen today but it will certainly happen at some stage. At what point do we say it is a terminal illness because there is nothing here that says that a person is in the dying stages of that illness? They go through a lot of steps, hoops and things to get through the criteria for this bill but if they really are in that terminal stage then how are they ever going to achieve that? Is it really going to work?

**Prof. OTLOWSKI** - The terminal stage can often go for months -

**Ms FORREST** - Years sometimes.

**Prof. OTLOWSKI** - Or years, so I do not see a difficulty in that sense. I think it is important that there are cooling-off periods and some safeguards in that respect. I acknowledge the difficulty in any definition. Sometimes I have seen bills where it has attempted to quantify in terms that the patient is going to die within a certain period, but I think that is an arbitrary approach as well. I agree that one could technically say that someone who is on treatment and who refuses to take that puts themselves in a situation where they will be terminally ill but I think the fact that it is couched in reasonable medical judgment brings in the objectivity of someone who is in a position where they are likely to die, rather someone who artificially is trying to bring themselves within the legislation if they are otherwise well and can respond to insulin and so on. So I would not have that concern necessarily.

There may be alternative definitions that the committee believes could be used that bring within it the dying phase or something of that kind, but it is important that this limitation is there, that it is not more readily available. Indeed I have even heard criticism of the bill that it is too restrictive, there are too many requirements and so on. So perhaps if people on both sides complain that is an indication that it is about right.

**Ms FORREST** - I did the flow chart of the bill. To go through that and get to the end in the top left-hand corner, for anyone on the north-west coast, Circular Head, the west coast, certain areas of the east coast and places like that, would be very difficult. We come back to the issue of the treating doctor as opposed to the medical practitioner; there are a lot of areas that do not really line up. If the first doctor, for example, usually the GP, does not want to be involved then trying to find another one is nearly impossible. Then you need the understanding of the illness and then either a palliative care specialist, who are thin on the ground, or a specialist in that particular illness, again thin on the ground, and then a psychiatrist. We can wait weeks for a non-urgent consult with a psychiatrist, so are the safeguards so onerous that if you live in Hobart you might be right but for anywhere else, don't worry about it?

**Prof. OTLOWSKI** - It is true that is a risk. The protections will be challenging to fulfil but it is important, if we are going to take a step towards legalisation, that there are safeguards contained in the legislation -

**Ms FORREST** - I couldn't agree more with that.

**Prof. OTLOWSKI** - One can see this in terms of a spectrum of possibilities. In the Law Society submission they are suggesting there should be even further regulation, there should be some review prior to the administration of euthanasia. They are wondering whether the documentation to the coroner after the patient has already been assisted is sufficient. One could suggest some judicial kind of review or some other investigation. We have to endeavour to achieve some sort of balance in terms of making things sufficiently available but then still having the safeguards in place.

In my writing in this area I have rejected suggestions for a more bureaucratised approach where you have to apply to a euthanasia referee or some tribunal for assessment, for the sorts of reasons that you are talking about. If you make it almost unachievable it is not going to help anybody. I do not know if there is any substitute for assessing the patient's competence, the need for independent confirmation of the patient's diagnosis and so on, but it does raise issues about equity and access and the things that we would need to do in terms of resourcing to ensure availability to people in all parts of the State. So I accept that is a challenge but I don't know if there is a better solution to it. If we think about what is happening at the moment and in what areas, there is an availability issue at present. People are well connected or not, so because it is not a lawful process there is real adhockery in terms of who can and cannot get access

**Ms FORREST** - If you make the option for voluntary euthanasia more accessible because we can see there is an issue here for the remote areas of our State, but without doing the same for palliative care, aren't we giving a terrible message? We make sure that you can go through these steps; we will make sure that we have psychiatrists available, that we have palliative care specialists to give advice on that matter, but we are not actually going to increase our palliative care services.

**Prof. OTLOWSKI** - I think we should be increasing palliative care whether or not we proceed with this legislation. Often society is judged by how it looks after its vulnerable people, and people at the end of their life need maximum options to make that process bearable.

**Ms FORREST** - Is there a risk that could occur by legislating in this area?

**Prof. OTLOWSKI** - From what I have said already perhaps it is evident but the greater risks are just ignoring what is happening. Here we can at least manage the risks and try to put resources into the areas where they are needed. There may be monetary implications for the health budget in order for this to be effectively implemented. It may be that people from the north-west need to be brought down for a period or into a major centre to facilitate such a request and to go through these processes.

**Ms FORREST** - Away from their family?

**Prof. OTLOWSKI** - Just for the assessment period.

**Ms FORREST** - But surely if we are going to make a law that facilitates this process, why should people have to travel to the other end of the State for this assessment?

**Prof. OTLOWSKI** - If there are resources to ensure that, yes, a psychiatrist will be available -

**Ms FORREST** - These are people who are already pretty crook.

**Prof. OTLOWSKI** - Absolutely. I think the principles are in place, they have integrity, so to water them down to cope with a minority in outlying areas would mean a greater risk of undermining what would otherwise be a cautious even-handed approach to dealing with this difficult issue. I acknowledge it would need to be worked through carefully in terms of fairness to people who may not be in urban centres.

**Ms FORREST** - The seven days and then the 48 hours; do you think that is enough time for people to cool off and think about it, once having made that first step to have time to process it? That first step would be the hardest thing for most people.

**Prof. OTLOWSKI** - Yes. The way the scheme works is that they have to be talking about it to the practitioner and then at a further stage request it and then it is put into writing. If you pulled out all the interventions or points of contact it would end up being over a period of time. If there is a concern about that then you can extend the days or hours as perceived necessary. These people will have been thinking about this prior to articulating their request, in any event.

There is one thing that I think could be improved and it relates to voluntariness. The bill is already very strong on seeking to ensure competence and that it is a voluntary request and that this is documented and so on. We know that the bill is derived from the Northern Territory legislation. One measure that I am on record for suggesting is that it is important that at the time of administration that voluntariness has been confirmed. At the moment that is not actually a requirement.

**Ms FORREST** - And that cuts out anyone that loses competence.

**Prof. OTLOWSKI** - Again, my advocacy in this area has been based on competence and voluntary euthanasia right through to the point of administration. That would be my preference. I am being consistent with what I have already had published. This is even if it is at the risk of some people being able to articulate a request and then not having that implemented. For that reason I am also on the record for saying I do not think advance directives are an appropriate thing in this area, that at some early point in your life you should say that, if ever this should happen to me, I want euthanasia. This intervention in a person's life is so important that we need to be absolutely sure that it is what that person still wants at the point of administration.

**Ms FORREST** - Margaret, I hear what you're saying and tend to agree with those comments. You're then going to be dealing with a small percent of people who will be able to fit right through to the end of it and then be assisted. Because of that, if we bring this law in - and I can see a lot of reasons why you would want to suggest that - are we going to find that doctors will have to do their own thing anyway, break the law because they can't get patients to fit under this?

**Prof. OTLOWSKI** - I can't deny that that would be a possibility, but for those where there is competence and where they can reasonably meet the expectations, clearly it will be a better pathway.

**Ms FORREST** - For that really small percentage.

**Prof. OTLOWSKI** - I am not sure it is so small. We are speculating about how many lose competence, especially if the time frame is quite a tight one.

**Ms FORREST** - If the time frame is too tight then you run the risk of saying that people haven't had time to think about it.

**Prof. OTLOWSKI** - Yes, that is why you need to have the balance. We are not talking about long periods of time between the signing the request and the opportunity for euthanasia to be administered. I think people would have to be fairly unlucky for them not to still be in a position where they can confirm their request at the point of administration. We need to be wary of not making assumptions that this will only be for a tiny minority. I think this would assist some and give peace of mind to many more.

**Ms FORREST** - But it is fair to say that this won't fix the problems of some people out there being assisted in dying, euthanased or whatever.

**Prof. OTLOWSKI** - Who aren't competent?

**Ms FORREST** - Yes.

**Prof. OTLOWSKI** - For my part, I am on the record for supporting voluntary euthanasia. I am not denying that. There is also the neonate area. We have incompetent people in our community in precarious situations in terms of their health and wellbeing. I don't pretend they raise easy questions. I find that a much harder issue to defend and to work out appropriate strategies for than when it is a competent person. Frankly, I see that as so straightforward if we are talking about voluntary consent. It is obvious to me that we should be responding to that. I don't deny that means that not all would have access; I accept that.

**Ms FORREST** - And there would probably still be illegal practices going on.

**Prof. OTLOWSKI** - Again, I can't deny that that would occur, but we would at least create a pathway for those who can meet the requirements.

**Mr GAFFNEY** - The issue of having to reside in Tasmania for 12 months, do you have any comment on why it is a safeguard or whether or not you agree with that safeguard?

**Prof. OTLOWSKI** - I do tend to agree with it. I think it avoids the kind of suicide or euthanasia tourism. We saw even with the brief experience in the Northern Territory that people were travelling there. People who were often very sick were travelling to that jurisdiction in order to gain relief. Our primary goal as citizens of this State is to look after our own constituents rather than become a repository, especially if Tasmania goes it alone and there isn't similar legislation in other jurisdictions. We have seen instances where countries have a more lenient approach. With Switzerland, for example, with its assisted suicide leniency, many people from the UK and even some from Australia go to that country for that purpose and I don't know if that is a desirable trend. I know we want to encourage tourism to the State, but not that kind. That is my own view.

**Mr GAFFNEY** - I appreciate that the main game is the bill, to get that to first base. Issues about funding for the north-west coasters or whatever is a side issue. The one that I am a bit more concerned about is the idea that this is to, in effect, protect our doctors who physically assist people to die. This morning we spoke to an ethicist, Professor Malpas, about the Oregon pill scenario versus injection. Even though he still believed there was a conflict there ethically, he could see how it was a bit of a grey area, removing the doctor one step further perhaps from -

**Prof. OTLOWSKI** - I totally agree in having doctors involved in assisted suicide but again with safeguards and the same sort of preconditions you would need to ensure competency and so on if it is a more removed activity. It also helps to ensure that voluntariness is there, that the patient can change their mind and so on. It would still need to be supervised. It is one of the things I was canvassing in my work because there is less resistance to that, and whether that would be a good solution.

My conclusion in that regard was that it would not be a solution for all people. Some people would be physically unable to commit suicide. One way to compromise is to say that for those who can self-administer then that should be the preferred option and that more direct assistance should only be sought or available for those who are not able to self-administer. But the same level of regulation is required, whether you are talking about doctor-assisted suicide or the doctor actually being the one to administer the lethal injection. Dr Rodney Syme has conveyed a similar view that perhaps that is one way in which we can minimise or reduce the direct involvement of doctors, as long as it is not the only option, as long as there is still the option for those who are physically unable but nevertheless competent and so on. That might be a way to have a two-tier or approach. I would not be opposed to that. Whether it is the patient putting tablets in their mouth or some other method, I do not see a big difficulty so long as it is overseen by a doctor, so if there is any problem with ingestion or so on they can come to their aid. I would not want people, in the expectation that it is going to kill them, to be in a position where that is not properly implemented, so it would need to be done with oversight. Doctors would need to be present and so on.

I would not object to trying to keep to an absolute minimum the circumstances where there is direct intervention by the doctor. This would go some way, I imagine, to placate bodies such as the AMA in terms of the doctor's role and so on, although they may even be opposed to assisting through provision of medication.

**Mr GAFFNEY** - One of the concerns of a good friend of mine who is a doctor is that he does not want to be put in the situation where he is being a part of the process. He is philosophically opposed to administering or giving any type of medication to end life but he believes he may be in a position where there may be indirect pressure because of his care for and relationship with his patient and their family and that he may then be put in a difficult situation.

**Prof. OTLOWSKI** - You have raised a very important point about voluntariness from the doctor's point of view. I think there is enough in the bill already but the message that would need to accompany all of this in an educative sense is that doctors must not feel compelled. There will always be some doctors who are willing to assist and that it really should be entirely voluntary from their point of view and their ethic and the whole package in terms of their relationship with the patient. There would be an expectation that they could refer the patient to someone else who is willing to assist but I would not want to put doctors in the position where they feel compromised.

**CHAIR -** Margaret, thanks very much for your presentation

**THE WITNESS WITHDREW**.

**Mr LUKE RHEINBERGER**, PRESIDENT, LAW SOCIETY OF TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** - Luke we have until 2.45 p.m. My intention is to hand over to you to present what evidence you would like to us. Thanks very much for the submission from the Law Society and then we will ask questions.

**Mr RHEINBERGER** - Thank you. Firstly I would like to thank the committee for the opportunity to appear today. I do not intend to add a great deal to the submissions that have been made.

For the record, I was to appear with the assistance of Anita Smith today. She was the driving force behind the submissions that are before this committee. She is an associate member of the Society, the Chair of our Elder Law Committee and is also President of the Guardianship and Administration Board. Unfortunately she is ill. That may mean that for of some of your questions I might to seek permission to provide written answers. Alternatively, I am sure that Ms Smith would appear separately if the committee wishes.

Before questions start I simply reiterate that the purpose of these submissions is not to take a moral or ethical position with regard to the bill. I understand I am opening myself up to lots of lawyer jokes there, but in all seriousness the Society does not see its role to take that position. It is a question for the Tasmanian Parliament whether this bill or one like it is passed. Our submissions are based, I suppose, on attempting at least to provide some assistance to the committee in respect of the present state of the law, where perhaps this bill fits into the legislative scheme that we have at present, and with regard to common law, and there are some comments on the structure of the bill. They are the only comments I would seek to make.

**Ms O'CONNOR** - Luke, are you aware of the paper was published in the *Medical Journal of Australia* in 2001, titled, 'The Intention to Hasten Death, a Survey of Attitudes and Practices of Surgeons in Australia'?

**Mr RHEINBERGER** - No.

**Ms O'CONNOR** - In summary, 683 out of 992 eligible general surgeons, so about a 70 per cent response rate, were asked the question, 'Have you ever, for the purpose of relieving a patient's suffering, given drugs orally or parenterally, bolus or by infusion, in doses greater than those required to relieve symptoms with the intention of hastening the patient's death?' and 36 per cent agreed that they had.

We heard from Professor Margaret Otlowski before who said that the way the law currently operates, there are acts of involuntary euthanasia taking place; that doctors are, out of compassion, administering drugs in full knowledge that it will hasten the patient's death. It has been put to us that that practice is either manslaughter or murder. Do you have a view on that?

**Mr RHEINBERGER** - On the present state of the law, there is a very grave risk that those actions would fall into most parts of the criminal code.

**Ms O'CONNOR** - Would accept that the legal framework, as it currently stands, inadequately protects the terminally ill in some cases because they have not given consent to this final act of medication?

**Mr RHEINBERGER** - I do not know if it is my position to say whether the criminal law does or does not protect people because there are lots of other issues in the subtext of what you are asking and, first and foremost, those are issues of consent. I do not know whether you are talking about people who have, for want of better words, consented to the hastening of their death, if that can be done at all, legally or illegally, by their doctor or by telling their loved ones. So it is a difficult question and I do not know that I have an answer for you on whether to the law adequately deals with it.

**Ms O'CONNOR** - Do you think the law provides any protection to vulnerable, terminally ill people in the final days of their lives, in terms of the doctor-patient relationship and potential involuntary euthanasia?

**Mr RHEINBERGER** - The law provides protection and, as you have said, if death is hastened illegally or unlawfully, that is a murder or a manslaughter charge.

**Ms O'CONNOR** - Have you heard of any convictions or prosecutions?

**Mr RHEINBERGER** - The next question might be whether the law is being used or whether those prosecutions are taking place? My difficulty is that I am not an expert in this area of the law. I am not an expert on palliative care. I am not an expert on the terminally ill. I have a problem, I suppose, in answering your question because of a lack knowledge, and I do not want to be seen as some kind of expert in those areas, which I am not and, with respect, that is not why I am here.

**Ms O'CONNOR** - Sure. In broad terms and taking into account some of the comments that you have made about the bill, do you think that it provides adequate safeguards and protection? There has been a lot of concern expressed by submissions, particularly from Christian groups, about the vulnerable who may be exposed to greater dangers as a result of this bill. Do you agree that the safeguards that are in the bill are very strong?

**Mr RHEINBERGER** - I think there are some dangers in the bill. A bill like this needs to be absolutely clear in its definitions and needs to be absolutely clear in the processes and procedures

**Mr WHITELEY** - Is it?

**Mr RHEINBERGER** - I think there are some difficulties in it. For example, if you read aloud clause 8, subclause (1), paragraph (k), it says:

> 'the certificate of request has been signed in the presence of the sufferer and the first medical practitioner by another medical practitioner (who may be the medical practitioner referred to in subparagraph (c)(i) or any other medical practitioner) after that medical practitioner' -

and on it goes. I think it could use some tightening up in its structure and definitions and it needs to be absolutely clear if a bill such as this is to be passed.

The other matter that we have raised is that of having some kind of review mechanism because at present there is not one in the bill. A person who is outside of the sufferer and the doctors, if they had a concern on the face of the bill, may think that there is no mechanism of review. Of course the Supreme Court has that power but that would take, I would have thought, someone to go and get some legal advice and a Supreme Court application. There are some areas that I think perhaps it would be reasonable to look at in terms of protection.

**Ms O'CONNOR** - Are you talking about protecting the interest of the wider family, as you have put in your submission?

**Mr RHEINBERGER** - If the wider family had a concern that someone's will was being overborne or that the doctors had made a mistake in saying that someone had capacity to make a decision of this nature, the protection is not only, I suppose, the family, the protection is also the sufferer, as the bill calls the person.

**Ms FORREST** - I have read your submission with interest and I was keen to talk to someone such as yourself who could go through the bill clause by clause. There have been a number of issues raised in many of the submissions relating to various aspects. You have already drawn attention to subclause (1)(k). I don't know whether you want to do that because I think there are a number of problems with definitions that have been identified. Even the residency clause, I would like to go through that. Is that an appropriate way to do this?

**Mr RHEINBERGER** - I am at your disposal.

**Mr WHITELEY** - I am presuming, maybe incorrectly, that in your submission - before it was put to print - either you or others in the office have been through this clause by clause?

**Mr RHEINBERGER** - Certainly we have read through it.

**Mr WHITELEY** - Have you made notations against each clause of concern?

**Mr RHEINBERGER** - No. The submissions that we have made are, I suppose, a lot broader than that.

**CHAIR** - Luke, would it be Anita Smith who would be more across this clause by clause?

**Mr RHEINBERGER** - It is probably fair to say that she may have given it some more detailed consideration than I have.

**Ms FORREST** - There has been comment made even with the act to confirm a right of a person enduring a terminal illness, and on it goes, in the long title - have you an opinion if there is such a right or are we confirming a right that doesn't exist here?

**Mr RHEINBERGER** - I think what the act is doing is giving the person a right.

**Ms FORREST** - So it's not confirming a right that currently exists? People have said there is no right in this regard and to say we are confirming a right is inaccurate; it should be to establish a right.

**Mr RHEINBERGER** - I suppose that is a philosophical as much as a legal question.

**Ms FORREST** - But is there legally a right that we are talking about here, for a person to end their own life in the manner described when they have a terminal illness?

**Mr RHEINBERGER** - At present not in the manner prescribed because the long title goes further and says:

> '… and to allow for such assistance to be given …' -

and certainly the thrust of our submission is that at present there is no right because it is a criminal offence pursuant to section 163 of the Criminal Code to instigate or aid another person to take their own life.

**Ms FORREST** - Short title, to die, within the act. If this is not really a legal question, tell me and we'll move on - the title itself - the Dying with Dignity Bill - suggests that if you die in other ways it is not dignified. Is that a fair comment or not?

**Mr RHEINBERGER** - I think you're right - it is not a legal question.

**Ms FORREST** - Do you want to express an opinion on it?

**Mr RHEINBERGER** - I think it is simply putting down what the author of the bill hopes it to be. That is about as far as I could take it.

**Ms FORREST** - Would you mind going through the definitions and identifying any problems that you see with them? Some concerns have been raised about the interpretation of 'assist'. What does it mean, particularly to people who are perhaps opposed to the principle and they may be working in a setting, say nurses or doctors, who may be required to assist in some way - even the ward aide may have to go to the pharmacy and pick up the medication? Are we assisting in that pathway - even the pharmacist who dispenses the medication from the pharmacy? People have raised concerns that they may be caught up in that and they do not know whether that provides protection for the doctor?

**Mr RHEINBERGER** - Again, I think that may have some validity. It is a matter of identifying it and fixing it if you can. In other words, you might say 'assist' is only used in relation to a person in respect of whom a certificate is enforced pursuant to this act. Then you have what 'assist' means so 'assist' only applies to that person.

**Ms FORREST** - It does not say that the way it is drafted.

**Mr RHEINBERGER** - Look, it may do. I would have to look and see where 'assist' is used elsewhere in the bill to see.

**Mr WHITELEY** - I know we are talking about the interpretation of the word 'assist' but this is pretty well where the issue of substance comes up to assist in the prescribing, the preparation of, the giving of or self - administration of a substance, and yet I cannot see where in fact 'substance' is clearly defined either. Have you any view or have you discussed within your peers?

**Ms FORREST** - It doesn't define it.

**Mr WHITELEY** - No. Is 'substance' limited to medicine? What does 'substance' mean? I know it is in the interpretation of 'assist'. Are these the sorts of things you are talking about as far as there may be some definition issues?

**Mr RHEINBERGER** - Yes. I cannot tell you what 'substance' means in terms of the bill -

**Mr WHITELEY** - You don't have the intent.

**Mr RHEINBERGER** - If it is not elsewhere.

**Ms FORREST** - I think it is really important that this is fleshed out a bit in that we have had a number of discussions about increasing the medication when treating a patient with a terminal illness. They are on morphine, midazolam, a range of different medications that could impact on that person's respiration or bring forward their death slightly - or maybe by a day, we do not know, okay? We are talking about a substance. A substance that will bring about the death is not one of those in itself generally unless you give a whacking great dose of it but to just have it as IV potassium that would cause someone to die, there are no two ways about that, that will kill them. A big dose of propofol, and they are not ventilating them, would cause their death too but you do not use potassium to relieve pain and suffering, for example, but potassium is a substance -

**Mr RHEINBERGER** - Yes.

**Ms FORREST** - and this is the question that we have. Some people deem it to be a fine line between upping the medication to relieve the suffering, knowing that you could have that double effect, as opposed to giving something that you know will kill the patient. That is something -

**Mr RHEINBERGER** - Yes, I think understand the distinction and why it is important.

**Mr WHITELEY** - But it is not defined, is it?

**Ms O'CONNOR** - Is it something that you could attach to the bill as a set of regulations or an adjunct to the current set of regulations in the Poisons Act.

**Mr RHEINBERGER** - I do not know if it is in the current Poisons Act. You could certainly put it into the bill.

**Ms O'CONNOR** - You mean in this act or in another? I wonder how you might, because you would not want to be too specific about the substance in the principal act.

**Mr RHEINBERGER** - I am not a doctor and maybe you would. I do not know. In which case you would call it an authorised substance and then you would have a definition of what authorised substances are.

**Ms FORREST** - This is in clause 23 of the bill.

**CHAIR** - I will draw members' attention to the fact that Parliamentary Counsel are our next witnesses and perhaps some of these questions could be directed at them in clarification of what might go in and might not go in. Luke has indicated that it is not a process that he can embrace at this time.

**Mr GAFFNEY** - I would like to hear comments on the structure of the bill. I would like you to elaborate on some of those points that you have made, why you came to that decision and some of the ways forward.

**Mr RHEINBERGER** - Clause 22 and in particular clause 24 of the bill dance around what it is trying to do. It is creating an exception to section 163 of the Criminal Code, which makes it an offence to assist someone in taking their own life, and it would not hurt if it said so. If it did so, it would be consistent with the rest of the bill.

We looked at clause 8 and we have recommended that it be broken down into its constituent parts. Perhaps what the drafter is trying to do is to say that we start here and these are all the steps. One of the difficulties or dangers is that a person loses themselves in that process. As presently written it is 'dense', so just break it down to a series of steps. That can be done in whatever way parliament would think is appropriate. For example, you might want to put the steps about time in one, the seven days and the 48 hours cooling-off period, and you might want to put the steps about the medical practitioners and the relationships they may or may not have to each other and the patient in another clause.

Again, that is on a global basis and I am sure that the Parliamentary Counsel would have a lot better idea on how that might be achieved.

**Ms FORREST** - There is no provision there if the sufferer loses capacity during the cooling-off period either. If someone loses capacity during the process then that is the end of the game, basically.

**Mr RHEINBERGER** - Yes. That is something that Parliament may wish to think about. That goes back to what we were speaking about a little earlier - whether there should be a review mechanism of some sort or a review body for circumstances exactly like that. The only body that can answer a question like that at present would be the Supreme Court. So perhaps thought needs to be given to some kind of expert body.

The other matter that we have raised is whether there ought be acknowledgement of the family relationships or the interests of spouses or family.

**Mr WHITELEY** - In being notified?

**Mr RHEINBERGER** - Yes, notification - and whether any act ought to make provision for what should take place at the time.

**Ms O'CONNOR** - In terms of notification, wouldn't that be a breech of the doctor-patient relationship for the doctor to tell the patient's family about their personal contact in regard to this matter?

**Mr RHEINBERGER** - It does not have to be the doctor. It can be a choice and simply be in the bill. It can be left up to the sufferer but at present there is no mechanism in there, though there is a mechanism for lots of other things to be brought up and discussed, including the effect. One of the things to take into account is the effect on the sufferer's family, so that is certainly in there. I am not quite sure how a doctor does that or what is being asked there.

**Ms O'CONNOR** - It is almost implicit, then, is it not, that there is respect for the family's -

**Mr RHEINBERGER** - I do not think it is implicit in there that the doctor will bring up, 'Who would you like to be there?'. That is probably one of the less important items in terms of the philosophy of the bill, but it is something that should be thought about.

The other matter we have mentioned is external scrutiny. It seems that the only external scrutiny at present in the bill is by the coroner and of course if there are any difficulties it is too late at that stage for there to be any changes.

**Ms O'CONNOR** - Professor Otlowski earlier put to us that the bill would be improved by confirmation of intent before the administration of the substance. Do you think that is a good point? So you have these steps all the way through where it is clear that it is still a voluntary act, but at that point where the final administration arrives you then ask the sufferer to confirm their intent and their wishes.

**Mr RHEINBERGER** - I do not suppose it could hurt. That is about as far as I could take that.

**Ms FORREST** - It does say it cannot have been rescinded in any way at any time. Under clause 12, a sufferer may rescind a request for assistance. That is a negative way because if you do not say 'I do not want to do it' then it is assumed that you do, whereas Professor Otlowski's suggestion was that you have positive test.

**Mr RHEINBERGER** - The other matters that we have raised concern the situation where a medical practitioner, an ambulance officer or someone else gives treatment or attempts resuscitation without knowing of the certificate. I think it is fairly important that people in those circumstances acting in good faith have some form of protection.

**Mr WHITELEY** - It could be somebody in an aged-care facility.

**Mr RHEINBERGER** - Yes - any potential circumstances where it might occur. It would be helpful, I think, if that was in the act.

**Mr WHITELEY** - It is a very important bill and if it became an act then obviously it would polarise community views and so on. Would you classify the bill in its drafting, from a legal point of view, to be minimally or significantly subjective, not in all aspects but in many of the aspects of the bill?

**Mr RHEINBERGER** - What do you mean by subjective?

**Mr WHITELEY** - You were saying before that some of the definitions need some tightening up. Maybe there is too much fuzziness. Maybe it is not sufficiently clear.

**Mr RHEINBERGER** - Without commenting on the rights or wrongs of the philosophy behind it, our view would be that the bill in its present form could use some tightening up. It could use some change in structure. It could use some serious thinking about some of the definitions.

**Mr WHITELEY** - When it comes to issues of breaches does that then connect with the Criminal Code? If there were to be a breach, at the moment it rests with the Coroner, pretty well. It's a bit late then.

**Mr RHEINBERGER** - A breach of this act?

**Mr WHITELEY** - Yes, so where do the enforcements aspects kick in, if somebody does the wrong thing at any point during this process? Should this bill codify for that or does it link then to the Criminal Code?

**Mr RHEINBERGER** - I must admit I have not given that aspect of it any thought. I do not know whether it is appropriate that a bill or an act such as this had criminal-type sanctions in it if they were not followed. Although, the flip side of that is it is very important -

**Mr WHITELEY** - Just on that point though. Isn't it the case that what we are doing here at the end of the day, in the words of Michael Tate who came and gave evidence, when we strip the bill back it comes down to the fundamental issue of withdrawal of prosecution under the Criminal Code. When you strip it all back you get to that.

**Mr RHEINBERGER** - That is why it needs to be very clear as to the steps that have to be taken and who falls in and out. There is a risk for a medical practitioner in particular. If they do not comply with an act such as this, then they are not acting pursuant to the act and then there is section 163 of the Criminal Code. One view is that they are simply instigating or aiding another person to end their own life unlawfully. This makes lawful conduct that would otherwise be unlawful. If you are not acting in conformity with this act, your conduct is unlawful. So the code comes in, yes.

**Mr WHITELEY** - Right, so the link for enforcement, for the want of a better word, then becomes the link to section 163 of the Criminal Code.

Should this bill have more clarity within it in relation to processes post-breach of any part of the bill? Should it or shouldn't it. I do not understand.

**Mr RHEINBERGER** - Do you mean criminally.

**Mr WHITELEY** - The process, I suppose, for it to be criminally pursued. It is not a trick question, I just do not understand it as I do not have a legal background. There is no hook in there from an enforcement point of view that I can see.

**Mr RHEINBERGER** - No.

**Mr WHITELEY** - None whatsoever. What happens if someone doesn't? Do they simply then get pursued under the Criminal Code because they did not fit within that?

**Mr RHEINBERGER** - Yes. Then the other question there is that the Criminal Code as it presently stands or do you give consideration to making fresh offences in terms of actions taken under the act. That is a whole different kettle of fish, I suppose, and that might range from advice that is given to people that the onus -

**Mr WHITELEY -** But should this then address that, do you think? This is a significant piece of legislation.

**Mr RHEINBERGER** - I think Parliament needs to address that question.

**Mr WHITELEY** - In an ideal world, though, if the bill was complete and tightened up and all the words you used, would a complete, tightened-up bill include issues to do with offences in breach of the act?

**Mr RHEINBERGER** -With respect, that is a question for the Parliament.

**Mr WHITELEY** - No, no. I asked whether a good bill would include that.

**Mr RHEINBERGER** - Well that depends on the lawmakers' view of any breaches. It is not up to me to give you a view on that. If you think that a breach or breaches of any part of this bill are sufficient and sufficiently important such that they should be met with some kind of criminal sanction, then of course it should.

**Mr WHITELEY** - Would other acts include such power to enforce?

**Mr RHEINBERGER** - There are lots of laws that include their own powers to enforce.

**Mr WHITELEY** - That is my point.

**Mr RHEINBERGER** - That could be anything from the Workers Rehabilitation and Compensation Act, which says it is a criminal offence to do certain things, to the Workplace Health and Safety Act and lots of others.

**Mr WHITELEY** - So this bill would not be devalued in any way if it had included within it such issues as we are discussing.

**Mr RHEINBERGER** - No, or there is the other way around it. It would not take anything away from the bill if it were to include the Police Offences Act or the Criminal Code - fresh offences. That is, you put a section into the Police Offences Act that deals with the Dying with Dignity Act and put offences under it. There are two ways to go about it. In my opinion, simply not having it in the act itself doesn't take away from or make any offence more or less serious.

**Ms FORREST** - I think it was Professor Otlowski who suggested earlier today that she could see some value in having a bill such as this for people who fit into a particular category, those who were in the process of dying of a terminal illness, and there were certain safeguards around it.  She also had some concerns about the process involved - the rigorous process of all the safeguards and the need to jump through all those hoops - but also acknowledged that there possibly should be a confirmation of that intent right before the moment.  I said to her, 'If you do that, there would probably be so many people who won't fit into it because they won't be able to meet all the challenges, so effectively you're only going to help the really small percentage of a small percentage who would even request it'.  Because of those people who might not be able to be helped because they either lose competence along the way or they do not fit under the interpretation of 'terminal illness' or pain and suffering or whatever it is, those people in that situation who are genuinely suffering without pain, we are then putting the medical profession in a position where through compassion they want to help them but if they do they then fall under the full weight of the law and the Criminal Code.

Are we creating another monster here?  It has become fairly clear that this bill will only cater for a very small percentage of the population.  There are people who don't have capacity, for whatever reason, but who are suffering greatly.  They may have had a stroke or may have dementia, they may have an acquired brain injury or be suffering psychologically, but they are excluded from this bill because they aren't able to give their consent.  Are we putting doctors in a position where they want to help but if they do then the full weight of the law comes down so they are not actually helping many people?

**Mr RHEINBERGER** - That is, I suppose, a philosophical question that I am unable to answer.  On the face of it, that seems to be a danger, given the hoops that people may have to jump through.  I don't know the figures, I don't know how many people it might affect.  It might be a danger and I suppose there is probably an argument to the contrary, that the numbers going to their doctors or bringing these questions up with their doctors won't change.

**Ms FORREST** - The question of wanting to be able to utilise that?

**Mr RHEINBERGER** - Yes.  I have to profess that is not my area.

**Ms FORREST** - If a doctor is inclined to want to operate under this bill, should it become an act, and then being excluded from a lot of those people who would participate, are they going to be put into a similar situation that we are in now?  Anecdotally, there are doctors who are going down this path -

**Mr RHEINBERGER** - That is probably a question you need to address to the medical profession rather than legal.

**Mr WHITELEY** - Clause 8(1)(b)(iii), on page 7 - in the definitions obviously an attempt has been made to define 'sufferer'.  Then it says:

> 'any medical treatment reasonably available to the sufferer is confined to the relief of pain, suffering' -

and then we move into a very interesting area, and I would like your legal view on it:

> 'and/or distress…'

I suppose these are the sorts of things that I was leading to when I used the word 'subjective' - that you weren't sure was the correct word, which is fair enough. From a legal perspective, when you see that wide description of distress, what alarm bells ring, if any?

**Mr RHEINBERGER** - I don't know that it is alarm bells, but I think you are right that the terms used there are very wide. They quite clearly go outside of pain and suffering and want to include the stress and it is an 'and/or'. So a person can bring themselves within clause 8(1)(b)(iii) by suffering distress alone and not undergoing pain or suffering. So it is very wide.

**Mr WHITELEY** - That is right because I suppose some the evidence we have had given to us by medical personnel would link issues to do with distress, anxiety and grief to this issue.

**Mr RHEINBERGER** - Certainly, that seems to be well and truly contemplated in that -

**Mr WHITELEY** - I suppose, when you are talking about terminal illness, intolerable suffering, even those who would be against the bill, would say, 'yes, okay, we can understand that', but when you move to this, my concern accelerates in that 'and/or distress' could be a wide-ranging -

**Mr RHEINBERGER** - I do not think there is any doubt about that.

**Ms O'CONNOR** - Could you improve that by taking the word 'or' out, or is does that make it too restrictive?

**Mr RHEINBERGER** - It might go too far the other way, that someone may be suffering intolerable pain but be at peace with themselves and if it were 'pain and distress', then you would take those people out.

**Ms FORREST** - Perhaps you can take out 'distress' altogether.

**Mr RHEINBERGER** - Yes. It is question for the Parliament about whether and to what extent mental anguish and distress should be taken into account in making these decisions.

**Mr WHITELEY** - If some other questions arise can we come back to you via your office?

**CHAIR** - I think Anita Smith might be keen to make a contribution if there are questions that we have. We will consider that.

**Mr RHEINBERGER** - Yes, certainly.

**CHAIR** - Thank you.

**Mr RHEINBERGER** - Thank you.

**THE WITNESS WITHDREW**.

**Ms RUTH HENDERSON** AND **Ms KATHERINE WOODWARD**, PARLIAMENTARY COUNSEL, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

**CHAIR** - Thank you very much for joining us today and, as you can see, I think members are keen to go through the process of looking at the bill and you are just the people to guide us through that process. Would you care to make an initial presentation and then we will come to questions from members?

**Ms HENDERSON** - Yes. What we thought we would do is provide a general feel for the bill purely from a drafting perspective. We have not looked at the Criminal Code or surrounding legislation. We have looked at this as a stand-alone document and we have some concerns with it as a bill. Then we will go through it clause by clause and work through the concerns.

Generally speaking, the bill is not drafted in accordance with Tasmanian drafting protocols and standards and that causes difficulties in a number of ways. There are minor inconsistencies, some of which, such as numbering, could be fixed up at the second print stage. References to some clauses are not made the way that we would do it in Tasmania. Those could potentially be fixed up at the second reading stage. There are other minor inconsistencies with the rest of the legislation on the statute book, such as the wording of penalty provisions and regulation-making power, but we do have other legislation, such as the Acts Interpretation Act, which can fill the gaps, so those are not major problems.

However, we have a number of major concerns with the bill because it does not follow drafting protocols. The protocols we have are to make sure that the bills are relatively easy to read and to reduce the risk of ambiguity. For example, a major problem that we have found is the use of 'and/or'. We would not use that in our office because it is ambiguous, and as we go through the clauses we will talk about how that causes difficulties with the bill and means that clauses can be read in more than one way. Those are the sorts of major concerns we have.

As the Law Society mentioned, we also have problems with the flow and the structure of the bill. The way that we usually try to draft a bill is to create a clear picture for the reader, particularly for medical practitioners who have to follow steps in order to avoid prosecution. We found a lack of logical progression in the provisions and we will talk about some of those where that may cause problems.

We also found the language quite difficult to read. It is not in plain English, the sentences are very long and in some instances there are two sentences in the one clause which result in a lot of ideas being crammed in. We found that some provisions were very difficult to understand and, if they are difficult to understand, there will obviously be more room for legal dispute and it is harder for medical practitioners to follow.

The other general criticism we had was the terminology; problems with definitions, problems with terms that are used in the bill that are not defined at all, and also the lack of internal consistency in the use of the language causes problems. Those were our major concerns.

What we thought we would do, if it is agreeable to the committee, is work our way through the bill clause by clause.

**Ms FORREST** - I have no complaints.

**CHAIR** - I am curious to see if there is anything to commend the bill.

**Ms WOODWARD** - The long title: while it may not be how our office would draft it, from a drafting point of view we could not see anything necessarily wrong. We are not talking about the terminology used there because it was not drafted in our office and therefore the terminology is up to the drafter, but there is nothing -

**Ms FORREST** - I raise the issue of the words 'to confirm the right'; there have been a lot of submissions saying that there is no such right, and that you cannot confirm a right that does not exist. Should it really be 'to establish the right'?

**Ms WOODWARD** - I agree that you cannot confirm a right that does not actually exist. Whether a right exists before this bill is in place is not up to us to decide, but if you feel that there is no a right preceding this bill then 'confirm' probably is not the right word because you cannot confirm a right that does not exist.

**Ms HENDERSON** - As I have said, we have only looked at the face of this bill, we have not looked at it more closely. I could not make a comment about whether there is an existing right at the moment, but assuming that there is not one then you could not confirm something that does not exist.

The commencement: the bill commences on the day on which it receives Royal Assent. That is not something that we would normally do in the office, particularly for a bill of this significance. The bill requires that a number of things be prescribed such as qualifications, et cetera, so regulations need to be in place before this bill commences. So ordinarily, we would commence it 'on proclamation' in order to give the medical profession certainty, and to allow all that is necessary to be put in place before this bill comes into force. Without the prescribed qualifications, for example, a medical practitioner cannot fulfil their obligations.

Interpretation: we have concerns with a number of definitions.

**Ms WOODWARD** - Before we address some of our concerns, I notice that you were raising the issue of the words 'substance' and 'assist'. Our office protocol is that, if it is not defined in the act then you would refer to the ordinary dictionary definition. It would be up to a court to decide how to interpret that, but if it came to us we would look at the dictionary definition of 'substance' which, as you say, is quite broad and covers more than medicine, but that would be how we would interpret the word 'substance' in this case. However, a court may interpret it differently.

**Ms O'CONNOR** - Which dictionary do you use?

**Ms WOODWARD** - The Macquarie Dictionary.

**Mr GAFFNEY** - So for clarity; if you were trying to improve this bill, you would suggest that a definition of 'substance' be included?

**Ms WOODWARD** - If the Parliament wanted to limit it to medicine. There is a provision further on in the bill that talks about the fact that a medical practitioner working under this legislation can do only what complies with medical standards, so they are not able to use a substance that would not normally be used for humans in this situation. It would depend on the policy behind what you wanted to do. There is that catch in there, and it would then be a case of determining the intent of using 'substance'; if you wanted it to be general or if you wanted to tie it down specifically to medical things.

**Ms HENDERSON** - The use of 'substance'. You are talking about using a substance and there is a general provision in there that says that a medical practitioner, clause 8(2), which says:

> 'In assisting a sufferer under this Act a medical practitioner must be guided
> by appropriate medical standards and such guidelines …'

so it is implying that whatever a medical practitioner does in assisting someone under this act, there has to be a medical basis for it. You are not necessarily talking about someone using something that would not necessarily be allowed under medical standards.

**Mr WHITELEY** - What if someone was to purchase such substance? It says, 'prescribe, prepare, give'.

**Ms HENDERSON** - The definition of 'assist' includes these things so it can include other things. It is not only *a, b, c, d*. The idea of that gives a flavour of the sort of things that 'assist' is meant to cover but it does not necessarily, it cannot, cover other things. That is why the term 'includes' is used so it could potentially cover that.

**Mr WOODWARD** - The next one we have an issue with is the definition of 'intolerable suffering' and this links back to that notion of and/or that is used in it. That is typically not used in our office because it can be ambiguous as to whether or not you need to just meet one or both of those criteria. I know when we discussed this earlier some legal practitioners in our office would use 'level of pain or distress' and 'pain and distress' and if you want to cover both areas that is what they would do. Because such a lot rides on this notion of intolerable suffering in the bill, to have an ambiguity of the use of 'and' and 'or' is certainly an issue.

**Ms FORREST** - In the one above, you have definition of 'illness' and you have a definition of 'terminal illness'. Is there any problem in the way that is done? It is talking about what an illness is and a terminal illness and in the way it is written that captures in the definition injury or degeneration of mental or physical faculties. Terminal illness in a long sense in relation to a sufferer means 'an injury or degeneration of mental and physical faculties which in the reasonable medical judgment within the normal course without the application of extraordinary measures or of treatment which would result in the death of the sufferer'. Is that exceedingly broad, in that it captures someone who has a degenerative mental illness, or just a mental illness, and becomes suicidal, which results in their death. It just seems a little all-encompassing of almost everything that eventually could kill you.

**Ms WOODWARD** - It is all encompassing but when you look at the application of the bill, you see that a medical practitioner has to be satisfied that the person is suffering intolerably, has a terminal illness and that there is not anything out there that can relieve their pain and suffering. It is broad but in the context that it is used it would not necessarily be -

**Ms HENDERSON** - We think that some of the terms there are very broad but in the context that they are used, and the stock checks, they are probably not too bad in the circumstances.

**Mr WOODWARD** - If that is the policy intent. If you wanted to tighten the bill and have it more specific, that is a question of policy and that is not a question for us in relation to drafting.

**Ms FORREST** - That is true. I am not of a mind of the person in charge of the bill, but there has been some suggestion that this really should only apply to people who are actually dying because people can be suffering a terminal illness for quite some time - sometimes many, many years before they die - and the definitions here do not actually articulate that in any way and neither does the content of the bill. So effectively someone who is diagnosed with motor neurone disease might decide tomorrow, 'I know what's going to happen' sort of thing or even cancer.

**Mr WHITELEY** - If it is terminal.

**Ms FORREST** - Yes, that is right. There are a lot of terminal illnesses and some of them go into remission, as we heard this morning from the MS Society. MS ebbs and flows a little - there is relapsing and remittent MS and then there is progressing MS. So people fluctuate in and out of these various states I guess. Do we need to nail that down a bit if we are to make it apply only to the people that it seems to be intended for?

**Ms WOODWARD** - Yes, you are quite right that there is nothing in there, as drafted, that actually limits it down to that. That is a question of policy as to whether or not you want to tie it down to that. I know that when we read it through, similar things came up in our general discussion of it in the bill but then we thought you also have to satisfy two medical practitioners and a psychologist to sign off and say that they are happy with that. Maybe that was the intention that that be the check and balance to stop people from being in that situation.

**Ms FORREST** - There is no requirement though to be in those terminal phases.

**Ms WOODWARD** - That is right. There is no requirement in there for that.

**Ms FORREST** - The end stages of the terminal illness.

**Ms WOODWARD** - Exactly.

**Ms HENDERSON** - Other definitional problems we found were one such as the medical practitioner. That has come up already, that it only covers a person who has been entitled to practise not someone who has a current practising certificate. You could have someone who 10 years ago was struck off and is not entitled to practise now but 10 years ago could practise medicine.  So we saw that as a potential problem.

**Mr WHITELEY** - It is obvious - but I just want you to clarify it - that this paves the way for anybody to fly in and fly out.

**Ms HENDERSON** - There is no residential requirement here.  Interestingly, later on the bill refers to the doctor being residential but it is not a requirement in this definition that the doctor be resident in Tasmania, so someone could fly in from interstate.

**Ms FORREST** - As long as they have been registered for some period of five years.

**Ms HENDERSON** - At some point in time.

**Mr WHITELEY** - In any State.

**Ms WOODWARD** - That is right.  It does not need to be in Tasmania.

**Mr WHITELEY** - So they could have been registered five years ago in Western Australia but are no longer.

**Ms HENDERSON** - That is correct.

**Mrs BUTLER** - And 'health care provider', is that a bit loose too?

**Ms HENDERSON** - We did not really have a problem with that in the context that it is used.

**Ms WOODWARD** - I did initially when we were talking about it being an institution but then when you look at how it is actually used, the definition does seem to fit where it is used.

**Ms O'CONNOR** - With the definition of 'medical practitioner' would the way to improve that be simply to say 'who is currently'.  That would deal with it, wouldn't it?

**Ms HENDERSON** - That is right.

**Ms WOODWARD** - Yes.

**Mr WHITELEY** - By linking a couple of these definitions together you can get a terminal injury.  Is that correct?

**Ms HENDERSON** - Yes.

**Mr WHITELEY** - Because under the definition of illness it says - and you have to watch these 'all' words, because they can disappear into oblivion - illness 'includes injury or degeneration'.  We suddenly put our attention on degeneration 'of mental or physical faculties'.  But prior to that, illness actually means injury.  Terminal?

**Ms WOODWARD** - Brain injury.

**Mr WHITELEY** - Terminal injury. Then it starts to open up a whole new -

**Ms WOODWARD** - The next definition we had an issue with was mentally competent and the most basic issue that we had with it is there is no 'and/or' between the paragraphs. That is a standard drafting practice in our case unless we say it means the following. Because there is no and/or, it is not clear whether or not for someone to be mentally competent they need to comply with one of the paragraphs or both of the paragraphs. As a lot rides on whether or not a person is mentally competent under this bill, that needs to be confirmed. Either way is up to a policy decision but there needs to be something in there to determine which way the definition is to be used.

**Ms O'CONNOR** - Realistically though, if we were to assume that either 'and/or' would be in there in terms of the bill it would be 'and' wouldn't it? If you linked those two -

**Ms HENDERSON** - If you want both it would need to be 'and' but, as I say, that is an issue of policy as opposed to how it would be drafted. If that came to our office that would be the first question we asked, 'Do you want both paragraphs met or are you happy with either paragraph being met?'.

**Ms WOODWARD** - The only other difficulty I had reading was with 'mentally competent' defined in terms of a verb whereas it is used as a noun. I think legally it still works but it does not work well in the context that it is used here. It means an ability and then when it is used as a noun it does not quite work in the context of the way it is drafted.

**Ms O'CONNOR** - If you were drafting that how would you improve it?

**Ms HENDERSON** - We had a talk about that. Instead of saying an 'ability' of the sufferer you would talk about 'mentally competent' in relation to a sufferer, which means that the sufferer (a) is able to do this and (b) is able to and so on. So I would phrase it not as a verb but as a state of being.

**Ms FORREST** - Just on that point, how do you determine capacity?

**Ms WOODWARD** - It is up to the doctor to be satisfied that there is capacity. To be satisfied that they have capacity they need to check that the person is able to understand those things and that they are able to make that decision freely and voluntarily after due consideration.

**Ms FORREST** - So do we need a defined capacity test?

**Ms WOODWARD** - That is a policy issue. The definition of mentally competent by itself is okay but if you wanted to tie it down to something that is more stringent, then you probably would.

**Mr GAFFNEY** - Isn't that in the application with the psychiatrist?

**Ms WOODWARD** - That is right. It is up to the medical practitioner and the psychologist to be satisfied.

**Ms O'CONNOR** - Trusting that professional judgment.

**Ms WOODWARD** - That is right, and because the people we are talking about are under such stress and pain it has probably been deliberately done this way so that they can use their opinion rather than having to meet a test that may not fit everyone in all situations.

**Ms FORREST** - When you consider some of the problems that have occurred with the Mental Health Act, which is another capacity issue, then we are looking at a similar issue here. Some of the issues are very similar. The Mental Health Act only applies to a small percentage of people with mental illness, so when we are putting such weight on this aspect of being mentally competent, would you normally try to determine how determination of capacity should be undertaken?

**Ms WOODWARD** - In this case we are talking about someone who is going in and initiating the process themselves, whereas sometimes in the Mental Health Act that is not the case and then you are talking about them being mentally unable to make those decisions.

**Ms FORREST** - We do have people who come under the Mental Health Act who are competent and have capacity but we still take their rights away.

**Mr WHITELEY** - For their own safety.

**Ms WOODWARD** - Yes, but in this case if they do not have mental competency, then under the act as it is it stops. If they are mentally competent they can say they do not want to proceed under this act, so it is a slightly different situation. If you wanted to ensure exactly what they needed to go through to prove competency then could be put in, but that is a policy issue.

**Ms FORREST** - Under 'qualified psychiatrist', there is no requirement here for them to be a Tasmanian. Is that important if they are going to be directly involved with the patients?

**Ms HENDERSON** - That is a policy decision. We would raise the issue with the instructing officer if we were drafting the bill and ask, 'Is this what you want?', but we would not make a call about that. That would be for the department to decide.

**Ms FORREST** - The fact that a person is entitled under a law of a State or Territory of the Commonwealth to practise as a specialist, does that indicate to you that it is a current requirement?

**Ms HENDERSON** - Yes.

**Ms WOODWARD** - Because if they are suspended or are refused registration then they are not entitled to practice under the law.

**Ms FORREST** - So formally entitled means current.

**Ms WOODWARD** - Yes. At this point in time they need to be entitled.

**Mr WHITELEY** - There is no time structure here at all. It could be a 20-year terminal illness or a two-month one. In Oregon I think there was a six-month time frame but here it is open-ended.

**Ms WOODWARD** - Yes.

We did not have any other drafting issues in relation to page 6. Clause 5 seemed to repeat a lot of the words that were used in the definition of intolerable suffering, but they are slightly different. If we were drafting this in our office I would be making sure that this differentiation is intentional because a court will look at that and say, no, that does not mean the same as the definition of intolerable suffering and therefore may apply a different test to it. Again, it uses 'and/or', which can be ambiguous.

**Ms FORREST** - In the 'mentally competent' definition, in (b) 'after due consideration', what does that say to you? What is 'due consideration'?

**Ms WOODWARD** - I think that probably ties more into how the definition of mentally competent is used, because we talk about medical practitioners being satisfied that a person is mentally competent and that the psychologist is satisfied that they are mentally competent. It is quite unusual for that to be in the definition rather than being in the provision where it is talking about someone making that decision.

**Ms HENDERSON** - Clause 7(1) refers to the 'termination' of a sufferer's life under this bill. That is one example of inconsistent terminology. Everywhere else it talks about 'ending' life and then suddenly here we are talking about the termination of a sufferer's life. If a judge was looking at this they would ask why is there a different term being used here, why is it 'termination' rather than 'ending'? I suspect a drafting error, but the terminology should be consistent.

**Ms WOODWARD** - Otherwise a court has been known, in cases like this, to say that a different term has been used here for a reason and has therefore applied a different meaning to it, but that might not be intention of parliament.

**Ms HENDERSON** - We had difficulty with clause 8(1)(b)(ii). I did get very confused reading it because a number of tests are being applied here. The medical practitioners are being required to apply an objective test in reasonable judgment about what is a subjective thing for the sufferer. So there is no medical measure acceptable to the sufferer. I am not sure how you would do that, how you could objectively assess a subjective thing that another person is experiencing. Also, I could not really work out what 'in reasonable medical judgment' was doing.

**Ms FORREST** - So how do you address that issue?

**Ms HENDERSON** - I would go back to the policy officer and say, what are you trying to achieve here. I do not quite understand what the test is meant to be here. You are asking a medical officer to make an objective test based on subjective -

**Mr WHITELEY** - But it is at the starting blocks. If you go back to 8(1) it says this is where we commence - a medical practitioner may assist. So we are out of the blocks, but only on the basis (a), (b), (b)(i) and (b)(ii).

**Ms WOODWARD** - But it is the notion that only if all of the following conditions are met. A medical practitioner applying the test in (b)(ii) needs to be satisfied of that before they can make their decision whether or not they are going to assist. If they do not know the test they are applying there, how can they be satisfied that condition is met?

**Mr WHITELEY** - Then it goes on to say, 'can reasonably be undertaken in the hope of effecting a cure'. There are plenty of people with terminal illnesses for which there is no cure in the offing, but they could live for 20 years.

**Ms FORREST** - We could be talking about a GP, an oncologist or a whole range of different specialists. The way I read this, they will be expected to know everything about everything. If I go to my GP and I have some fairly rare cancer that is terminal, I am expecting my GP to know all the medical measures that could be acceptable to me, that could be reasonably undertaken. Is that asking too much of any medical practitioner, to try to jump through this hoop, or for the patient to jump through it with the medical practitioner?

**Ms WOODWARD** - That is a question of policy. All we can say is that, at the moment, as it is drafted, it does seem quite conflicted within the provision of what it is asking the medical practitioner to do.

**Mr GAFFNEY** - Do you think that is possibly why they have put in a safeguard to have a second medical practitioner's opinion, hopefully to have that discussion with the first one to say, 'What are your understandings? What are your specialities?'

**Ms WOODWARD** - Yes, that is the intention but the problem is that as it is drafted it is not clear enough that that is the intention.

**Ms HENDERSON** - And they have to be satisfied of that in their own right.

**Ms WOODWARD** - That is right, before they even bring a second medical practitioner.

**Ms HENDERSON** - The paragraph below that, (iii), has the same problem with the overall pain, suffering and/or distress. Once again it is an ambiguous use of the 'and' or the 'or' and there would need to be a policy decision about how that was used.

**Mrs BUTLER** - In (ii), is it okay to have 'reasonable' and 'reasonably' there?

**Ms WOODWARD** - It is used twice but that is where it is getting to mental illness and that is part of the problem.

**Ms HENDERSON** - The next issue is with paragraph (d).

**Ms FORREST** - Before you move to that - Paragraph (c)(i) reads:

> 'one of which is a medical practitioner who holds prescribed qualifications, or has prescribed experience, in the treatment of the terminal illness from which the person is suffering; and'-

so t goes on. Is it clear from this what sort of qualifications and experience are required, or do you need regulations to underpin that?

**Ms WOODWARD** - That is what that is getting at. By saying 'prescribed', it actually means prescribed in the regulations.

**Ms FORREST** - Can you prescribe experience then in the regulations? Is it reasonable to do that?

**Ms WOODWARD** - Yes, it is reasonable to do that.

**Ms HENDERSON** - On page 8, clause 8(1)(d) refers to 'the illness is causing the sufferer intolerable pain or suffering'. The defined term is 'intolerable suffering' and 'intolerable pain' is not defined. I assume that it is possibly a drafting error and that it should be just referring to 'intolerable suffering' but if a new concept is going to be brought in like 'intolerable pain or suffering' it needs to be defined because it has no meaning in the current context.

**Ms WOODWARD** - That is right. It would rely on the dictionary definition.

**Mr WHITELEY** - You are not the first person to raise that issue.

**Ms WOODWARD** - Good.

**Mr WHITELEY** -In the sense that they are two very different things.

**Ms WOODWARD** - That is right.

**Ms HENDERSON** - That was the only major issue we had with page 8. We will move onto page 9.

**Ms FORREST** - Just the expression in (g), which reads:

> 'the medical practitioner is satisfied that the sufferer has considered the possible implications of the sufferer's decision to his or her family'.

In your mind is that just to ascertain that, yes, I have told my family this is what I intend? We are looking at the implications for the family - and there could be some very good implications because they might come into a huge inheritance or the family could be absolutely devastated to think that that family member might be going to take that path for whatever reason. Does this actually tell you what is expected to be achieved in this?

**Ms HENDERSON** - It is a very subjective test for a medical practitioner to do.

**Mr WHITELEY** - It links a little bit to where Luke was at before, where he summed up and said that maybe from a policy point of view we have to look at whether anyone else needs to be aware of this. Cassy then raised the issue of privacy and -

**Ms WOODWARD** - And as it is currently drafted, it does not require the sufferer to discuss it with his or her family, just that the sufferer is aware of the effect it may have on the family and, as you say, that might be a devastating effect but all the medical practitioner has to deal with as it is drafted is that they are aware of that effect.

**Ms FORREST** - Or that they have considered the implications.

**Ms WOODWARD** - That is right.

**Mr WHITELEY** - Not done anything about it, but -

**Ms WOODWARD** - That is right, they have considered it.

The next issue that we have is in paragraph (k) on page 9 and that is because at the end of that paragraph it refers to 'the above conditions have been complied with'. We looked at that and asked whether we were talking about the above conditions in paragraph (k) or the conditions in paragraphs (a) to (j)? It is not necessarily clear and yet again because the medical practitioner has to be satisfied at every single one of these paragraphs they need to know exactly which conditions we are talking about here.

**Ms HENDERSON** - The next concern we had was actually on page 10, paragraph (p). The way that this is drafted, with the 'and/or' followed by another 'and', is very ambiguous.

**Ms WOODWARD** - We had a lot of arguments and came up with three different meanings of what it could be.

**Ms HENDERSON** - Three different meanings of what potentially could occur. It could be that the medical practitioner has to provide the assistance and remain present while this assistance is given. It could be that the medical practitioner himself or herself provides the assistance and then alternatively is or remains present while the assistance is given. The way it is drafted it is completely ambiguous. There are three different options and it is not clear whether the medical practitioner has to stay if he gives the assistance or if someone else gives the assistance. From a policy perspective someone would have to sit down and say, 'Okay, what exactly are we asking here in terms of who has to stay, and at what stage'.

**Ms FORREST** - So if someone else gives the assistance - and this is one of the things that bother the nurses - this leaves it open for the nurse perhaps to give that assistance and they are not covered at all under the protections of the legislation.

**Ms WOODWARD** - That is part of the problem. At the moment in paragraph (p) it is not clear who provides the assistance and who needs to remain present until the death of the sufferer.

**Ms HENDERSON** - You could interpret it in three different ways.

**Ms WOODWARD** - We came up with three but a court could quite easily come up with a fourth or fifth one.

**Ms FORREST** - So is that a way of getting out of hanging around as a medical practitioner?

**Ms HENDERSON** - If I were a medical practitioner I would be very worried about what exactly I was supposed to be doing because it is not clear enough.

In subclause (3), the words 'If a sufferer's medical practitioner has no special qualifications' are very ambiguous, in our view.

**Ms WOODWARD** - It is not a defined term. It later goes on to talk about special qualifications in the field of palliative care as are prescribed, but that only refers to the second time 'special qualifications' is used. It does not necessarily mean that when we are talking about special qualifications to start with they need to be prescribed. Also, what is considered 'a special qualification'?

**Ms HENDERSON** - It could be some formal qualification or it could be a night course or a weekend away - it is not clear.

**Ms FORREST** - It might be in a book.

**Ms HENDERSON** - Yes, it is ambiguous. It does not give guidance to the medical practitioner as to whether they are considered to have special qualifications in that sort of palliative care, and if they do or don't whether they need to refer to another person. It does not give enough guidance.

**Ms WOODWARD** - It is especially highlighted because if they do refer it to someone else they need to have special qualifications as prescribed. That one is made clear but the first one is not.

**Ms FORREST** - So where is it saying that someone's qualifications must be prescribed?

**Ms WOODWARD** - At the end of the line -

> '… the availability of palliative care must be given by a medical practitioner (who may be the medical practitioner referred to in subparagraph (1)(c)(i) or any other medical practitioner) who has such special qualifications as are prescribed.'

That means prescribed in the regulations.

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**Ms HENDERSON** - We had a number of issues with clause 9. There are a lot of new terms introduced that are not used elsewhere in the bill and are not defined. We have new terms 'adult sufferer' and 'treating doctor' so that clause 9 does not seem to fit in with the rest of the bill. Does the term 'treating doctor' mean something different to the medical practitioner or does it mean the doctor at the actual time? It needs clarification as to what exactly is meant by 'treating doctor'.

**Ms FORREST** - There is also someone who may have performed surgery - for example, a mastectomy that might lead to chemotherapy and radiotherapy so you have the surgeon, the oncologist and the radiologist.

**Ms WOODWARD** - That is right. It does not link to when they need to be treating the sufferer at any time. It is not talking about the person who is providing the assistance because in previous cases we talk about the medical practitioner providing the assistance whereas here we are just referring to the 'treating doctor'.

**Ms HENDERSON** - It is not clear who it is who needs to be resident in Tasmania - which person in the chain of events needs to be resident. Subclauses (1) and (2) of clause 9 do not seem to sit together either. In subclause (2) it talks about there being a requirement to stay for 12 months but in subclause (1) it doesn't. The two don't seem to work together at all.

**Ms FORREST** - I had a real query about this one. I did a flow chart of the bill and I was stuck here because if the sufferer is domiciled or ordinarily resident in the State, what does that mean?

**Ms HENDERSON** - We had exactly the same question.

**Ms FORREST** - If you go on to 'or', I thought it should have been 'and' because I would have thought I could move over this week and be ordinarily resident if I change my address -

**Ms HENDERSON** - That is right and that was part of the issue with having the minimum 12-month period for (2) but not for (1).

**Ms FORREST** - You would have to have 'and' then, wouldn't you, at least?

**Ms HENDERSON** - That is right, or at least move up the minimum of 12 months to both, so you have that requirement for them both.

**Mr WHITELEY** - I also took it that you could have lived here for 12 months 10 years ago.

**Ms WOODWARD** - Exactly.

**Mr WHITELEY** - In clause 9(2), 'the sufferer has had his or her settled or usual residence in the State for a minimum of 12 months', the wording 'has had' implies that the sufferer could have moved to the Gold Coast, which many do, but could still fulfil the residency requirement by having lived in Tasmania previously. That is the haziness that you are talking about?

**Ms WOODWARD** - Yes, that is right. The other issue we had was the fact that they are talking about providing the assistance and, if we were drafting this, we felt that clause 9 would be better included in clause 8 as one of those tests to be done before you get to providing assistance.

**Ms HENDERSON** - Otherwise you have the medical practitioner going through all of the steps and then coming to clause 9 and saying, 'Oh, you are resident in New South Wales'.

**Ms FORREST** - Sorry, back you go.

*Laughter.*

**CHAIR** - Is there much more to go? We are past the time when our next guests are due, and I am wondering whether we could have a lunchtime gathering perhaps tomorrow with whoever is available? I know there will be three of us here.

**Mr GAFFNEY** - I think this is really good and I think we need to give it appropriate time.

**CHAIR** - This is really very helpful, but I realise our other guests are here and I do not want to be extending through the afternoon.

**Mr WHITELEY** - We can decide the time later, as long as the ladies are happy to do that.

**Ms HENDERSON** - Yes, that is fine.

**CHAIR** - We were not sure what we were going to get, but we realise now it is quite detailed and we appreciate that. Thank you very much for your evidence so far and we will communicate with you through Charles and probably try for a lunch time later this week.

**Ms HENDERSON** - Thank you.

**THE WITNESSES WITHDREW**.

**Dr MARTIN MORRISSEY** AND **Dr JOANNA BAKAS**, ROYAL AUSTRALIAN AND NEW ZEALAND COLLEGE OF PSYCHIATRISTS, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

**CHAIR** - Martin and Joanna, thank you very much for attending today and we will be interested to hear your evidence and then to ask questions and delve a bit deeper. I wonder whether there is something you would like to present to us first and then members will ask questions.

**Dr MORRISSEY** - I have written down a few thoughts on paper and you are welcome to have these but they are really just to pin my thoughts on.

**CHAIR** - Maybe you would care to talk to them?

**Dr MORRISSEY** - I might start by describing - and perhaps it is relevant to Joanna too - what I do. I am what is called an old-age psychiatrist. I specifically see older people. I have been qualified as a doctor for about 19 years and much of my work, not surprisingly, revolves around older people and also seeing people in what is called 'a liaison setting', that is people who are ill in hospital.

**Ms FORREST** - A psychogeriatrician?

**Dr MORRISSEY** - Yes.

**Dr BAKAS** - I am also a psychogeriatrician. I am the chairperson of the local branch of the Royal Australian and New Zealand College of Psychiatrists. That is why I'm here today. I've been qualified and working for a similar length of time to Martin.

**Dr MORRISSEY -** We have tried to canvass the views of our colleagues in the State and we have been met mostly with a lot of silence. So I think is important to say that what we say here is not necessarily representative of our colleagues in the State, but we have tried, obviously, to be as representative as we can.

A couple of initial observations: psychiatrists do have expertise in the recognition of mental illness and some role in the evaluation of people's capacity and competence, so clearly, these things are core to what has been put in the bill. Having said that, I certainly think a large number of our colleagues would be reluctant to participate in a process that involves euthanasia, and some of them do not wish to have anything to do with it at all. I do not have an accurate view of what the view is across Australia or Tasmania. Where that specific question has been looked at in Europe, generally the figures indicate that about two-thirds of psychiatrists are not comfortable with participating in euthanasia in any form.

**Ms FORREST -** How many psychiatrists do you have in the State at the moment?

**Dr MORRISSEY -** Thirty-odd, I think.

**Ms FORREST -** That is not a huge number, so we must be weighted down at the Hobart end, are we?

*Laughter*.

**Dr BAKAS -** We are.

**Ms FORREST** - Fifty per cent of the population is in the greater Hobart area.

**Mr WHITELEY** - You're a legend!

**Ms FORREST -** Seriously, I would not have thought there were anywhere near that many, to be honest.

**Dr BAKAS** - Some people work part-time. Those figures are available; I do not know them off hand but we could certainly provide them.

**Dr MORRISSEY -** There are not huge numbers. Some of them work in quite specific areas of practice, for example, psychotherapy.

**Mr WHITELEY** - Just on the reluctance issue - I know we are now starting to get a little subjective - but you are pretty well saying that two out of every three would be reluctant to participate. What do you think this reluctance is built on?

**Dr MORRISSEY -** I think a big part of that is that most of our work revolves around people preventing people from dying - preventing people from killing themselves - and also trying to engender hope in people despite what is going on in their lives. We try to give hope to people whose lives are not happy or ideal. I would add that it also extends to seeing people who are in the late stages of illness and trying to look at ways of giving them hope and giving them a sense of purpose in what they do. That is a core part of our work, so assisting in the process of euthanasia, for many people, presents difficulties.

**Dr BAKAS** - Martin and I have discussed this and, speaking for ourselves and other people we have worked with, we are not against palliative care, and a very aggressive and assertive palliative care. I do not think any of us would be against withdrawing treatments, for example, if a person wanted that to happen or providing as much pain relief or relief for agitation as is necessary for the person to have a reasonable quality of life, despite the fact that that might actually lead to their life being shortened, but the primary goal would not be to end the person's life.

**Ms O'CONNOR -** It has been put to us by a number of submissions that what is sometimes described as good palliative care is, in fact, involuntary euthanasia. We have a paper here that was published in the *Medical Journal of Australia* in 2001, which demonstrated that of about 680 general surgeons who responded to this questionnaire, about a third said they had administered medicine to the sufferer knowing it would relieve pain but with the intent of ending life.

**Ms FORREST** - Hastening their death.

**Ms O'CONNOR -** Sorry. I meant to say hastening their death.

**Ms FORREST -** It makes a big difference.

**Ms O'CONNOR** - Yes, it does; I agree.

**Dr BAKAS** - I suppose it is your intention that matters - and the fact that you obtained a consent from the person?

**Ms O'CONNOR** - It is what they are saying here. It's essentially what this evidence is demonstrating, is that in some cases there is no consent from the patient.

**Dr MORRISSEY** - I would make a couple of comments about that. First of all, with due respect to my surgical colleagues, I think they tend to see the world in slightly more black and white terms than general practitioners, palliative care doctors and psychiatrists, for that matter. Maybe proponents of the bill might ask surgeons to participate in that process.

The other thing I would say about it though is that I think you mentioned involuntary euthanasia. I don't think you can use that as a reason for the bill - these are people working outside of what this bill would do -

**Ms O'CONNOR** - Sure, but what we are saying is that out there in the medical fraternity in Australia, acts of euthanasia are happening in an unregulated way.

**Mr WHITELEY** - That is one of the pieces of research.

**Ms O'CONNOR** - Dr Otlowski's paper is worth reading in terms of the references.

**Dr MORRISSEY** - I think you need to drill down exactly into the explicit details of what people are doing in those circumstances. Certainly a lot of people, when they talk about end-of-life care, are talking about withdrawing treatment, not giving treatment, or using medications which they know will hasten someone's death but not necessarily with that being the primary aim of it. Some of the bits and pieces I have read do not define those things as clearly as that.

**Ms O'CONNOR** - I think there is a lot of grey.

**Dr MORRISSEY** - Yes. I want to talk a little about competence but one of the things that the bill does not address is people who are minors, people who are significantly cognitively impaired or people who are otherwise unable to give their consent to a process.

I mention that because when the public generally think about the arguments for euthanasia, a lot of the time they are thinking about that group of people. For example, the child who is paralysed and comatosed with an advanced brain tumour; the elderly person who is profoundly demented, sitting in a vegetative state in a nursing home; the teenager who is in a vegetative state after a car accident or something. I wonder if some of the impetus to support a euthanasia bill is driven by a desire to help those people when, in fact, this bill is not going to do that. I would say that from the point of view of support for the bill. I wonder if that is what a lot of people think of.

One of the things that I encounter very commonly - and other people might have their own views on this - when people talk about wanting to die and concern by family members about someone dying without dignity, is that consideration has not been given to not treating things or to palliating someone's symptoms effectively. The occasions when people specifically ask me to help them kill themselves - and obviously I have a select biased sample of people, which is fairly uncommon - a fairly significant proportion of those people appear to have a mental illness. They are actually depressed and that can obviously happen concurrently to their malignancy, but a very big proportion of them have not had a clear discussion about, or a clear understanding of, what can be offered to alleviate their suffering, their distress, concerns about their dignity.

**Ms O'CONNOR** - That is a requirement in this bill.

**Mr WHITELEY** - Just on that point. Do you think that as a profession your expertise is then sought early enough, outside this whole discussion, or do you think sometimes it is often left too late in the piece.

**Dr MORRISSEY** - I think the involvement of palliative care is often not sought when it should be or sought later in the course of a person's illness than it should be. My experience in terms of working with palliative care, both here and in New South Wales and overseas, has been that the involvement of a good palliative care team addresses pretty much all or most of the concerns that a person has about pain, suffering, loss of dignity and their care needs.

**Mr WHITELEY** - Which would include your input as a professional?

**Dr MORRISSEY** - It may or may not. I suppose we get referred - this is what I was talking about - our selection bias in that we get referred people, I suppose, where it is a concern that they may be depressed as part of their illness.

**Ms FORREST** - On that point that you raised about people tending to throw everyone into the same barrel here - the 16-year-old left in a vegetative state following a car crash and people who have an acquired brain injury that cannot make decisions for themselves. We have surveys go out asking whether people are supportive of law reform to address the issues of people wanting the option of relief from that suffering. Do you think, if it's all thrown into one basket, then we are not really pulling it apart and saying, 'Well, we agree with withdrawing treatment where it's futile or not commencing treatment if it's futile or refusing treatment which is every patient's right to do so as long as they have the capacity' - and then you get the guardian to make that decision, obviously -

**Dr MORRISSEY** - Yes.

**Ms FORREST** - So, are we putting it all in together and not really getting a true picture of what people are supporting when they answer that question?

**Dr MORRISSEY** - I'm just commenting on what I hear people say o me. When they think about the situations in which they think there are good reasons to have euthanasia, a lot of the time they're talking about those sorts of situations that are not covered by this bill. The reason I make the point is that if the bill is being put forward as a means of giving voice to those concerns, then it doesn't give voice to those concerns.

**Dr BAKAS** - I have had people referred to me in another State who were requesting help to kill themselves or they were going to do it themselves. They were actually depressed. It might have been because I am a psychiatrist, but that wasn't the request of the treating team - it was when I was working was in a liaison role in a general hospital. There were a number of people who, once you treated the depression, could actually have a reasonable quality of life.

**Ms FORREST** - Getting back to the issue of capacity then, is the question -

**Dr MORRISSEY** - It's a pretty thorny one.

**Ms FORREST** - Determining capacity - the test, and what do you do? How do you manage that as a psychiatrist?

**Dr MORRISSEY** - Well, it's task specific, so, in very general terms, determining whether someone's competent to make a particular decision about having a urinary tract infection treated, versus having various forms of chemotherapy for a particular type of malignancy, they involve different thresholds. Generally, the weight here, the problem that's been, or the question that's being asked, the higher the bar you want someone to jump over in terms of their level of competence, there are not many things that are more significant than deciding whether to end your life. So, in principle, that requires a very high level of competence, whatever that means. I make that comment because when you think about someone, for example, with an advanced malignancy they'd be on a couple of opiates, for example, for their pain relief, so often these people are not in pristine cognitive shape. The requirements are that the person sort of broadly understands the nature of their illness, that they've been able to weigh up the pros and cons of it.

**Ms FORREST** - Yes - it says 'understand the benefits and risks' - I've been given this information - 'understand the general nature of the illness or condition, understand the benefits and risks of, weigh the pros and cons of, presented medical treatment and palliative care options and then the capacity for the sufferer to make decisions and the decision freely, voluntarily, after due consideration.'

**Dr MORRISSEY** - Yes, that seems a bit fuzzy and it's probably less than the sorts of requirements for making a will. It's just an observation in the sense that how do you define that and also this group of people may well be impaired to some degree.

**Ms FORREST** - So, if you were the psychiatrist that I, as a GP, referred Mr Finch to, ow would you go? I know it would be a challenge but how would you assess his competence in that regard?

**Dr MORRISSEY** - Okay, well, I'd want to get a general idea of his cognitive functions. I might ask him some tests just to test a number of facets of his cognition - memory, orientation, and those sorts of things. I would want to get an idea of what he understood his illness to be, what were the treatment options that were available to him and what he saw as the pros and cons of those options. I would also, and this is one of the things that concerns me a little bit about the bill, is the lack of requirements of involvement for the family for two reasons. One is, ending someone's life does not occur in isolation and if we look at the effects of suicide, say in the context of depression or anything else, that has a profound effect and can have a profound effect on people's families. Maybe I have misread the bill but it does not seem to put a great deal of weight on what might be the views of the family. The second part about family that concerns me is that one of the things about assessing someone's competence and assessing whether or not someone might have a mental illness requires getting corroborative history from people like family or a GP or something like that. So if someone comes to me saying, 'I want to end it all, this is hopeless', one of the first things I will do is sit down with their spouse or their son or daughter and say, 'Well, okay, how long has dad been thinking about this? Have there been any changes in his sleep, his mood, his appetite?' So I would be looking at the things that might indicate the presence of -

**Mr WHITELEY** - So such an assessment is not going to happen in half an hour, is it?

**Dr MORRISSEY** - Absolutely not.

**Ms FORREST** - How many appointments do you think reasonably you would need? I know that every situation is unique and every situation is quite different, but realistically how many times would you need to see a person. If your first contact with Mr Finch is today when he has come along and you have no other - except his referral letter -

**Dr BAKAS** - We can all pull ourselves together, can't we, for half an hour or an hour. We can wear our nice suit.

**Ms FORREST** - He is doing a good job, isn't he?

**Dr MORRISSEY** - It will vary for the individual. For example, if they are a bit fuzzy because they are a bit zonked out with the morphine or something, that will require that we see them at a different time. I just want to emphasise the importance of getting corroborative history.

**Ms FORREST** - Which may take some time to get.

**Dr MORRISSEY** - It might take some time to get but of necessity it involves families. So there is a bit of a discrepancy there.

**Mrs BUTLER** - This morning we had some evidence about stress levels of health professionals who are treating people who have been terminally ill. I wonder if you would like to speak to that. What sorts of supervision you would work with yourselves. How you get rid of your own stresses and if you would like to comment on the desensitisation of doctors who work with people in this situation.

**Dr BAKAS** - I suppose it depends which area you look at. People in both palliative care and oncology become quite stressed and there is a lot of burn out. I think particularly people working with oncology patients, staff can actually have to leave or can become quite emotional - and I suppose that could affect decision-making and interactions. I think we really need to look at this. Here we are looking at people being involved in euthanasia aren't we? You have to be very careful about the qualifications of people, that they are not overloaded, that they receive support. One of my concerns, thinking about this, was who are the psychiatrists? Who are the psychiatrists who are going to do these assessments? Not every psychiatrist necessarily has experience in assessing capacity. Are we going to have a few psychiatrists in the public system who are already overloaded. I am sure there will not be huge numbers coming through anyway from overseas. I think people expected it and it didn't happen but just make sure that the resources are there, that the proper assessments get done. Is that what you are looking at?

**Mrs BUTLER** - Yes, it was around that point.

**Dr MORRISSEY** - People who work in, for example, palliative care, by and large choose to do that. So they have a comfort, I suppose, at one level with it. It is certainly is a distressing thing.

As I mentioned before some of the most distressing folk are people who are not going to be addressed in this bill, particularly young kids.

**Mrs BUTLER** - What about desensitising of doctors?

**Dr BAKAS** - Not so much in palliative care perhaps, but I think particularly in other areas that is an issue. It's not something that I've looked at in the literature but, having worked in my past life for a short while in some haematology, for example, I think that people can become desensitised and perhaps not consider referrals to palliative care when they're appropriate. I think that's what worries both Martin and me. I mean, why are the surgeons doing this; why haven't they referred these people to palliative care? That is my question.

**Mrs BUTLER** - I understand that the highest level of your code of ethics is preservation of life. I wonder if you'd like to comment on this bill's impact on your practice in terms of the code of ethics.

**Dr BAKAS** - In the United States medical practitioners participate in torture - not in torture, but assessing people in the army. We don't do that here; we would be deregistered. Do we really want to change that?

**Ms O'CONNOR** - With respect, someone who is diagnosed with a terminal illness or is suffering from motor neurone disease and is at the end of their life in absolute agony is a different matter. The medical statistics tell us that for between 5 per cent and 10 per cent of these patients palliative care does not provide relief. Is that not a form of torture that we as a society don't provide them with some relief? They are a very small group of people, but they are a group of people right now who are suffering.

**Dr BAKAS** - My concern is that there is a far larger number of people who could be helped by properly resourced and available palliative care but who don't have access to that. As a society, if we are putting euthanasia as a first option rather than actually upping our services and resources -

**Ms O'CONNOR** - No, we're not because the bill makes it very clear that you have to go through the steps of making sure that palliative care isn't providing the relief and what's happened in Oregon where they've had the laws in place for 11 years -

**Dr MORRISSEY** - I don't know that the bill does that. I think it -

**Ms O'CONNOR** - Well, they have to be satisfied they've talked to them about palliative care and it's not providing the relief.

**Dr BAKAS -** Does it address having the resources though?

**Ms O'CONNOR** - No, because that's a policy matter. Sorry, but, with respect, what's happened in Oregon where they've had these laws for 11 years is that they have what is regarded as the best palliative care system in the United States because more resources and more focus were put onto palliative care. So, they have to complement each other, which is what this bill recognises and what the experience in Oregon has been.

**Dr BAKAS** - I just worry about the order, that's all. We are talking philosophy now rather than practicality about what you do first; what you put in place first.

**Ms O'CONNOR** - Palliative care is the first stop here.

**Dr MORRISSEY -** It almost sounds as if you are trying to use the bill as a means of achieving better palliative care services.

**Ms O'CONNOR** - Certainly not. There has been agreement around this table every time we've had the discussion, and with witnesses, that palliative care services are deficient and need more resources, but that's a separate policy issue because for some people palliative care doesn't provide relief. So, as psychiatrists, what's your solution for these people?

**Dr MORRISSEY -** Well, I've not seen that number of people, to be honest with you.

**Ms O'CONNOR** - Well, they probably don't go to psychiatrists, maybe at that stage of their lives.

**Ms FORREST** - Psychiatrists should be involved in palliative care though.

**Dr MORRISSEY -** Yes; but, as I say, I can't think of a single instance where a person receiving good palliative care has not had their symptoms and concerns addressed to their satisfaction.

**Ms O'CONNOR** - We've had senior palliative care experts in here who've said that these people exist.

**Dr MORRISSEY -** Sure, I'm just commenting on my own experience.

**Mr WHITELEY** - They've placed no number on it, by the way, but said they do exist in the minority.

**Ms O'CONNOR** - Well, she was the head of palliative care here for -

**Mr WHITELEY** - Well, she didn't say 5 or 7 per cent.

**Ms O'CONNOR** - No, but that's what the doctor said this morning.

**Dr MORRISSEY -** I would think it might be a smaller proportion than that. Perhaps people have terminated their own lives.

**Ms O'CONNOR** - I have one last question. When the Australian Christian lobby made its representation it was put to us that a desire to end life is an abnormal state. I'm really interested in this place in psychology because is it abnormal if we are approaching death to accept it and is it abnormal to want to get out of an excruciatingly painful physical situation? Isn't it paternalistic to suggest that?

**Dr BAKAS -** But we don't say that.

**Ms O'CONNOR** - No, I'm not saying that of you.

**Dr BAKAS -** We would not. That sometimes is a problem; people say that somebody must have had a mental illness because they took their own life. In the vast majority of cases that's true but not always if people don't have an illness and they have capacity. You really have to look at this very carefully, though, and I think it's addressed in the bill. People can have pressures put on them; they can feel, for example, a burden to their family. That's often the sort of situation we address, which is why Martin was talking a lot about the importance of involving family and finding out what's happening. It's not always so clear-cut, so you want to make sure the decision is not being pressured in some way. It's a complex matter, that people aren't being pressured by family because it is costing them a lot of money, or they're having to do lots of care because they're not getting support from community services and things like that.

**Ms O'CONNOR** - The evidence out of Oregon is that there doesn't seem to have been any issue with pressure or with the slippery-slope argument; it hasn't happened.

**Dr BAKAS -** I've read that too in a number of countries where it has taken place. There hasn't been the huge number that people expected.

**Mr GAFFNEY** - You mentioned at the beginning that there are probably about 30 psychiatrists in Tasmania.

**Dr BAKAS** -We'd have to check.

**Mr GAFFNEY** - You said that it was hard to get information from them. Are you aware whether your colleagues would agree to participate in or are supportive of this bill and the intent of this bill?

**Dr MORRISSEY -** In terms of those that have spoken up, I'm more aware of the ones who very clearly do not want to participate - and I would hesitate to say that therefore the ones that haven't said anything would be happy to participate.

**Mr GAFFNEY** - So you haven't had anyone that said yes, I think this -

**Dr MORRISSEY -** No, so I can't answer that question.

**Dr BAKAS** - But we haven't had time to do a proper survey.

**Dr MORRISSEY -** No and as a group we are blooming hopeless about articulating our views in these circumstances.

**Mr GAFFNEY** - We've had some very articulate, professional people come in and say that we shouldn't assume that the general public are not aware of euthanasia and the importance of this bill. We shouldn't just assume that, simply because they perhaps don't come from the same educated background. If a person says, 'I am in pain, I am aware, I don't want to leave the world in this way, I don't want my doctor to be a criminal, I want to leave in a manner of my choosing', then I believe that's a very positive and rational choice. They don't want to go down and they don't want to say, 'No more medication so I will die a painful death'. They want to opt out of this world in the way that they see fit. That's the argument we get presented to us. This is the issue, you assess the problem, this is how they want to go and they want to do it in a way that they believe is dignified. How do you not say, 'Okay, I've ticked this box, yes, yes, yes; it's all there; they're fully competent; they're aware of where they're going to go'. Why don't we allow that to happen?

**Dr BAKAS** - It's very rarely quite so simple. That tick-a-box idea worries me. Life's very rarely so simple. People might have a doctor who is very keen to get them better and keep them alive as long as possible - very well meaning. There might be other options that they haven't been offered. There might be other pressures that we don't know about. You really have to do a very thorough assessment to see exactly what's going on for that person. It's not because I don't respect the person and their capacity to make the decision for themselves but just to make sure that there aren't other matters that we haven't addressed.

**Mr GAFFNEY** - I got the impression from the submissions to us that people haven't gone into this with a not-feeling-well-today sort of attitude. This has been something they have considered for a long time. They have done enduring guardianship and they're aware of all those sorts of things. So it's not a lack of knowledge or understanding.

**Dr BAKAS -** Sure. Some of the people we see are more the other way. The person now has dementia but has expressed a view in the past and we have family members we are talking to and who are responsible under the act. Often nobody has talked to them about palliative care and that we can withdraw. Why are they having 20 drugs to keep them alive?

**Dr MORRISSEY** - Or why did they have their last episode of pneumonia treated? It is just obscene.

**Ms FORREST** - We do not let people die of natural causes very often.

**Dr MORRISSEY** - It surprises me how often people are not aware of that.

**Dr BAKAS** - It is not a painful death. It is not an undignified death. You can give medication to make sure people do not feel short of breath or do not experience pain.

**Mr GAFFNEY** - One of the things that came out of the Oregon experience was anecdotal evidence that when people walked out with the tablet or pill there was a little bit more assurance that they were more in control of their life and how that decreased the anxiety.

There have been 431 deaths over the last 11 years that have used that. So it took away some of the concerns that may have led to depression or second-guessing.

**Dr BAKAS** - There are certainly people to whom I have spoken who have managed to look it up. It is very easy to find out how to kill yourself. That is the other way, if you are physically able and can have access to the Internet. How long did it take you, Martin?

**Dr MORRISSEY** - Five seconds.

**Dr BAKAS** - I have had patients in private practice who have been very unwell and who had told me they had their store of medication if things came to that extent, and they did feel better knowing that. On the other hand, people with motor neurone disease and quadriplegia et cetera are often being kept alive. People have been treated for their pneumonia. There are similarities. People are actively admitting them to hospitals, giving them intravenous antibiotics.

**Ms O'CONNOR** - But with motor neurone disease it is such a terrible process of degeneration before they are even at the stage where treatment could be withheld.

**Dr BAKAS** - Often lots of pneumonias and things like are treated early. I wonder if people are told about it and given their options.

**Dr MORRISSEY** - They are a prime example of a group of people where the involvement of palliative care teams early on in the piece has been very helpful in addressing those persons' concerns, and it has not reached a stage where they have been in pain and distressed and undignified.

**Ms O'CONNOR** - Do you know the case of Robert Cordover?

**Dr MORRISSEY -** No.

**Ms O'CONNOR** - He was a motor neurone sufferer who ultimately took his own life a couple of months ago because he did not want to go down that path.

**Dr MORRISSEY** - So he made the decision and he had the means to end his own life?

**Ms O'CONNOR** - He made the decision that he did not want to live to the point where he could not do anything for himself.

**Dr MORRISSEY** - So why would he need someone else to end his life?

**Ms O'CONNOR** - I understand that he did need or requested assistance.

**Dr BAKAS** - That was the other question we came up with. If people have the physical ability and they have the means to take their own life in a way that was not painful, why would you need to involve someone else? I know there are cases where that is not possible, for example if someone is a quadriplegic.

**Ms O'CONNOR** - When they are physically disabled.

**Dr BAKAS** - But for people who are not physically disabled, can you ask the medical practitioners to do this?

**Dr MORRISSEY** - Or ask anyone. That is what is being asked, for someone else to end my life. Of necessity that is going to involve someone else.

**Mr WHITELEY** - How quickly can depression come upon someone?

**Dr MORRISSEY** - You would want to have the corroborative history.

**Mr WHITELEY** - You are 60 years old, relatively fit, watching your grandkids starting to arrive and then suddenly you are given the diagnosis that you have six months to live. Depending on your personality and so on, can depression come upon you very quickly?

**Dr BAKAS** - You might be looking at two different things. Most of us, when we receive bad news, especially something like terminal cancer, might not develop what we call a major depressive disorder but might be shocked -

**Dr MORRISSEY** - Angry.

**Dr BAKAS** - angry and upset, but you might work through that and in a couple of weeks time you may not feel the same way. You would not even necessarily look at medication for someone like that. You might just look at supportive therapy. They may not change their opinion. We all go through difficulties in life; something awful happens, a child dies in our family or something dreadful happens, and we feel depressed and angry and we might act in ways that we later regret.

**Mr WHITELEY** - It would highly unlikely for any of us, as strong as we all might think we are, to get some sort of news such I just described and not move into a state of distress. We had some discussion with Parliamentary Counsel and the Law Society in relation to the terminology. It would be highly abnormal not to go into a state of distress.

**Dr BAKAS** - When people become angry they sometimes want to kill themselves or someone else. You would want to provide services for that group of people too.

**Mr WHITELEY** - The earlier the better.

**Dr BAKAS** - That is right. Depression is a bit different and affects people over a period of time.

**Mr WHITELEY** - There are other factors in play.

**Ms FORREST** - One quick question. There has been some comment that the psychiatric assessment should not be necessary, two doctors should be enough. If the bill were to be supported would you favour this provision being retained in the bill or would you rather leave it out.

**Dr BAKAS** - I think it should be retained; particularly to make sure people do not have a mental illness, have the capacity and are not being coerced. It is a very complex area and it is not black and white.

**Dr MORRISSEY** - My broad view of the legislation - and I am going to offend someone here - is that it seems very clumsy, but it is very hard to have all the necessary checks and balances in place and have a workable bill.

**CHAIR** - We thank you very much for the evidence you have given.

**<u>THE WITNESSES WITHDREW.</u>**

**Dr PHILLIP NITSCHKE** WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** (Mr Finch) - Thank you very much, Dr Nitschke, for taking the trouble to travel interstate to give evidence to our inquiry. We appreciate it very much. I will hand over to you to make a presentation and then we will ask some questions.

**Dr NITSCHKE** - I appreciate the opportunity to speak about this and it was worth the effort to come down from Darwin to speak. I am looking at the Dying with Dignity Bill as a person who strongly supports the right of people in certain circumstances to get lawful help to die. It is a well-known position and you won't be surprised to hear that. The reason that it is important to comment about the bill and to bring some reflections and perspectives to this particular piece of proposed legislation also comes from my experience. I was in an unusual position, and I guess I still am in Australia, as the only doctor who has had experience helping someone lawfully to end their life. That was in and under the brief-lived Rights of the Terminally Ill Act in the Northern Territory in 1996-97. I thought it was a very progressive and quite civilising piece of legislation, and I note with some interest that the wording of the current Dying with Dignity Bill here in Tasmania reflects that bill very closely and I think that is of great interest and something that I, by and large, support.

My experience though during that period of time when I helped four of my patients to die was not without difficulty. I do not want to give the idea that my support for such legislation suggests that the model that we used back in 1996 somehow or other represents the best that can be achieved. In fact, there were a number of things wrong with that particular piece of legislation - and you will be aware that it was overturned by the Federal Parliament of Australia - Territories being considered to be places that were unable to make such legislation - with the passage of the Kevin Andrews bill. That is not a problem in Tasmania but we, of course, had to then bow to those particular restrictions and the bill after only eight months was overturned and the four seriously ill people that were my patients had the peaceful death that they wanted. I should point out that all of those four felt they were in the right place at the right time. Each of them said almost that same statement to me before they died. They said, 'I feel so lucky that I am in a place where this has been seen to be important enough for legislation of this nature to be enacted'.

As I said earlier, it was not without problems and I think that some of those issues do need to be looked at. In fact at the end of that period I looked very closely at the law in conjunction with a Professor Kissane, who was the Professor of Psychiatry at Melbourne University, and is now at Sloane Kettering Medical School over in New York. Professor Kissane was strongly hostile or had a strong position of opposition to the idea of legislation for voluntary euthanasia. From the perspective of a palliative care specialist from a psychiatric perspective, he reflected many of the views that you have had presented to you that this is not an area where the medical profession wants to be engaged. However, I thought it would be worthwhile to work with this person who had a clear position, given that I had a clear position, so that we might come to some position where we would learn by bouncing off each other's ideas and looking closely at the experiences of those eight months. We came up with some information and we put it together in the form of a paper, the 'Seven Deaths in Darwin' paper, which I provided for the committee, and which was published in the *Lancet* journal in 1998.

Many people refer to that article usually, I might add, when they are trying to complain about or point to what they see as reasons why a government should not go down the path of trying to introduce legislation to try to codify when a person can get help to die. In fact you have had some evidence presented to you in some of the earlier presentations where people have quoted from this paper 'Seven Deaths in Darwin' and, more specifically, quoted from Professor Kissane. I have read the transcripts of the information or the report that was provided to you on 10 August and I have seen it come up. In one of the pieces of evidence that was provided by Mr Wallace of the Australian Christian Lobby. He went on to say that this particular paper simply demonstrated the farce of euthanasia safeguards. In other words, he was suggesting that this particular publication shows that it is impossible to legislate for this issue.

I strongly disagree with that and what I wanted to do was to say that, yes, there were problems but they are not insurmountable. Yes, there are difficulties and we need to look at them and I do not think it is worthwhile reinventing the wheel. I think if one is going to look at legislation that parallels very closely this previous existing legislation let us look at the problems and faults of that and move on and make sure that we do not fall into the same traps.

I looked, and with the help of Professor Kissane, we identified several problems. Those several problems I have listed in the submission that I handed to you, not in great detail, and I thought that I would just list them with some explanatory sentences but really provide you with the detail that you might want. Some of the issues have come up in other people's presentations but briefly they are that the biggest problem we identified was the fact that the particular legislation that is being proposed here and the legislation that I worked under sets up the medical profession as the keepers of the gate. They are the people who have the keys to decide whether or not a person is given access. Demonstrating whether a person has eligibility to use such a piece of legislation is one of the biggest difficulties and you have seen much argument today in the little period of time that I have been listening to this, much argument about how do you make sure that the person who goes forward and in some way or other is accepted to get help to die is, in fact, eligible. By and large demonstrating eligibility is turned over to a panel of doctors and doctors do not find this an easy task at all. Giving the keys to the gate to the medical profession brings about problems and, as this proposed legislation does exactly that, I anticipate problems there. Some of the problems I have listed in point 2. One is differing medical opinions. You will get one doctor who says that this person is not terminally and you will get another doctor who says this person is terminally ill and because of the definition problem over the issue of terminal illness, which has come up already, you can see that both have quite valid arguments and the patient is left caught in the middle.

What we found in the Northern Territory was that people's decision about whether a person was terminally ill could largely be linked to whether they were supportive in principle to the question of whether a person had the right - in other words, whether or not they were philosophically on-side. We saw this in the case of the second patient who had an unusual skin condition called mycosis fungoides. A dermatologist, who was strongly hostile to euthanasia, insisted that she was not terminally ill. Another dermatologist, who was supportive of voluntary euthanasia, insisted that she was terminally ill. It seems that there was no difference in the dermatology - this is a skin disease - but there was a big difference in their attitudes to this issue, so putting medical professionals in this role leads to difficulty.

The role of psychiatrists is the third point. We have just listened to the explanations and comments by the Royal Australian and New Zealand College of Psychiatrists and many of the comments that were made there are ones I have heard before and I disagree strongly with many of those comments. That is the attitude of many people within the psychiatric profession and I think they summed it up very accurately when they said there will be people who simply will not engage with this. You have 30 psychiatrists in Tasmania - not a lot - and so there could well be difficulty there.

One suggestion by a person who gave evidence to your committee earlier, complaining about what happened in the Northern Territory, made reference to the fact that psychiatrists were brought into the Northern Territory to help the terminally ill obtain the signature they needed. That is not surprising because we had only four psychiatrists in the Northern Territory, so we had to bring them in from outside.

Palliative care is being cast as an opponent to voluntary euthanasia. That was identified by Kissane and myself, and unfortunately that is what happens when you start having people go through this difficult process of assessment. They are worried about palliative care. They know that they have to have palliative care options explained to them. They have made a decision themselves that they do not want to go down that path, but they know that if they are seen to be resisting in any way the strategies proposed to them by palliative care professionals they may be ruled ineligible and you get a degree of deceit creeping into the patient's presentation of themselves. They are so desperate to pass this difficult assessment that they start to reconstruct, re-invent and re-present their medical situation so that they pass.

I have mentioned the problems of the definition of terminal illness. They come up a lot because, as people point out, diabetes is a terminal illness. Of course it is a terminal illness because if you do not have strategies and treatments acceptable to the patient, you can be expected to die of your diabetes. People have said that is a reason why that definition needs to be tightened. By and large though, I think the definition that you have used here is a good one, and you should resist the idea of putting some particular time frame in. The idea of suggesting that you have to die within six months, using the Oregon example there, or some period of time, I think is fraught with an equal number of difficulties.

The final point I want to bring up really summarises all of the issues; that is that the medical assessment was viewed by patients as a hurdle to overcome. I spoke with Marshall Perron very early in the piece when he was proposing the legislation, and he said, 'I don't want this to turn into some sort of nightmare so that seriously ill, suffering people find themselves having to jump through hoops.' Those were his words. What we ended up with was a bill where seriously ill, suffering people jumped through hoops. It was an ordeal that they saw themselves having to face and to confront and ultimately to try to pass. It was like some bizarre and rather macabre, final examination.

When Bob Dent, the first man in the world to ever receive a legal voluntary lethal injection on 24 September 1996, finally got that rigorous and arduous assessment completed - he received four signatures on a piece of paper - I said, 'Congratulations, Bob, you have qualified.'  He looked at me and he said, 'Qualified for what?  Qualified to die?'  I said, 'Yes, Bob, you have qualified to die.'  In some ways, the irony of his comment draws attention to the fact that what we had set up and created was this very difficult process to which we were subjecting the most unfortunate people and which they had to confront if they wanted to take this path.

I realised that if each of those four people had had the drugs in the cupboard - drugs which are not that easy to obtain despite what your previous speaker said - but if they did have the right drugs in the cupboard they would not have been using that law.  Why would you go off and see a psychiatrist and have your sanity checked if you had the drugs in the cupboard?  You would just go to the cupboard.

That is the situation.  I think there are probably better way to deal with this.  I am very much in favour of the Swiss system, which uses the slightly different approach of decriminalising the idea of assisting suicide.  If you go down the path that the Netherlands, Belgium, Luxembourg, Oregon and Washington have followed - that is, to try to codify conditions when a person can get help to die - you will have these issues.  I think with a bit of clever initiative you can avoid some of the pitfalls that might follow.  That is my summary, and I would be pleased to answer any questions.

**Mr WHITELEY** - We have had some discussion in relation to who is a medical practitioner, a qualified psychiatrist, and residency issues and so on and so forth.  What was the issue in relation to the second death in Darwin - was it Janet Mills?

**Dr NITSCHKE** - Yes, Janet Mills.

**Mr WHITELEY** - What was the situation there where there seemed to be a question mark hanging over the qualifications of the psychiatrist?

**Dr NITSCHKE** - It was not the qualifications of the psychiatrist, it was the qualifications of the specialist who was supposedly knowledgeable in the field of the disease.  She was a person with the unusual skin condition, mycosis fungoides.

**Mr WHITELEY** - A lot of itching.

**Dr NITSCHKE** - Yes.  In fact she was not complaining of pain she was complaining of unrelievable itching.  The specialist reports that I referred to came from interstate.  There were no dermatologists available in the Northern Territory and she came with two specialist reports, one saying she was terminally ill and one saying she was not.

**Mr WHITELEY** - What did the autopsy find in that case?

**Dr NITSCHKE** - I do not think the autopsy did anything else other than to say that this was a person who had serious mycosis fungoides.  The point about the specialist, though, that you are asking -

**Mr WHITELEY** - Psychiatrist.

**Dr NITSCHKE** - It was not the psychiatrist. The psychiatrist was happy that she was of sound mind and able to give consent. You had to have a specialist registered in the Territory who was able to effectively say that this was a terminal illness. There was no specialist in dermatology in the Territory who could do this, but the way that particular legislation was worded, any specialist could do it, so we really asked every specialist in the Territory, and the only person who was prepared to wave his hand around in that difficult situation had no dermatological qualifications, but he felt so distressed at what he saw was the suffering of this individual. It was an orthopaedic surgeon who came forward.

**Mr WHITELEY** - So you can understand why some people would be asking questions on two fronts with regards to the Janet Mills' case. Can I just clarify with you, the psychiatrist that was part of the process was in fact a forensic psychiatrist?

**Dr NITSCHKE** - In the case of Janet Mills?

**Mr WHITELEY** - Yes.

**Dr NITSCHKE** - Forensic psychiatrist? Yes, all right, I will accept that.

**Mr WHITELEY** - I have the same stuff here.

**Dr NITSCHKE** - Yes.

**Mr WHITELEY** - It says 'that a forensic psychiatrist who lacked experienced in working with the medically ill reviewed her. He judged her depression to be consistent with her medical condition'.

**Dr NITSCHKE** - Yes, all right.

**Mr WHITELEY** - I am just asking the question in relation to our questions of definition of a qualified psychiatrist. In the case of the second death in Darwin it was a forensic psychiatrist that gave the tick off, is that correct?

**Dr NITSCHKE** - That is true, but this idea of insisting that people have certain levels of qualifications to be able to sign off and whether a person can give consent is one that you have just been listening to.

**Mr WHITELEY** - I hear what you are saying, but this bill actually goes to the definition - well, it does not in some ways - of medical practitioners and qualified psychiatrists. So in this particular case as you have just acknowledged, because the specialists were not available in the end, the one that came forward was an orthopaedic surgeon.

**Dr NITSCHKE** - Yes, that is right.

**Mr WHITELEY** - Under the act he or she was allowed to actually sign off.

**Dr NITSCHKE** - That is right.

**Mr WHITELEY** - Even though there was no direct relationship to the actual illness.

**Dr NITSCHKE** - Absolutely, and that was one of the failings of the legislation, but you could see it more as a result of the number of medical practitioners in the Northern Territory. It is not likely to happen here.

**Mr WHITELEY** - So none of those things - the forensic psychiatrist, an issue to do with the depression not necessarily being diagnosed, and then an orthopaedic surgeon turning up to tick one of the boxes - were technically or legally a breach under the legislation.

**Dr NITSCHKE** - No, they were not technically a breach under the legislation; in fact, it was clear that the most controversial of all those issues was the orthopaedic surgeon signing off on a dermatological case. That was controversial. No-one questioned the so-called forensic psychiatrist except Kissane. Most people were of the opinion that you did not actually have to be a psychiatrist to be able to make these decisions. The idea of elevating it to that level was even questioned because you are effectively making the bar that you have to jump over higher and higher to satisfy the people that were worried -

**Mr WHITELEY** - I do not disagree with that.

**Dr NITSCHKE** - No, but you end up with a piece of legislation which is unusable. In fact the first person who came to Darwin to use that law was a taxi driver from Broken Hill. I could not get any doctor to see him so he turned around and drove back to Broken Hill. He was dying of stomach cancer. No-one doubted he was dying but I was then rung up by the head of the College of Physicians in Darwin who said, 'You have got your law but you are never going to use it. We will make sure it never works'. Effectively they were saying to me, 'You are stuffed. We are not going to cooperate. Where are you going to go now?'. It was in that highly emotive and politically involved environment, where there was a battle going on between different factions within the medical profession, that the orthopaedic surgeon who disliked what he saw happening to this poor woman stepped in and said, 'I can do it'.

**Mr WHITELEY** - I want to come back and ask you some specific questions in relation some of the vagueness around the bill. We had this discussion with others earlier about depression and so on and so forth. In the case of intolerable pain and suffering, which we have spent days talking about, you are quoted within this Kissane report that you did not consider his pain to be excessively troublesome.

**Dr NITSCHKE** - That is true.

**Mr WHITELEY** - Rather, you recalled him weeping, saying he felt it pointless to continue suffering. So in the context of that, what comments would you like to make to the committee because you have some fairly strong views ultimately - not necessarily under this bill - in relation to who should be able to access such liberty, freedom, choice or whatever you want to call it. Would you like to comment in relation to the depression and mental health challenges?

**Dr NITSCHKE** - The hardest area to comment on is depression and the mental health challenges. In terms of the degree or the extent of Bob Dent's suffering, which was your earlier reference, Bob Dent was suffering from a lot of symptoms, and pain was not necessarily the one that was causing him the biggest trouble. It was the crippling effects of the breathlessness, which had been partially relieved by blood transfusions as he became increasingly anaemic, to the point where he said, 'I am not having another blood transfusion'. That meant that as his blood count dropped he simply could not get his own breath. The subjective suffering associated with such symptomatology may not be painful, but in a sense it was worse to him than the pain that he would be experiencing from some of the other aspects of his cancer.

Your other question was about the degree of depression. As we said in the report that we published here, symptoms of depression were common. Symptoms of depression are very common in people who are dying. The question is: are they able to given informed consent? Are they able to make rational choice and that is a very hard question. There is a lot of disagreement within the psychiatric profession on how you assess capacity. You heard earlier that to assess capacity to decide whether you should die should have the highest requirement. What they seemed to be saying was that you had to be of total clarity to have the capacity to assess whether you want to die. Other people disagree with that. They say it is a simple decision. Do you want to live or die? You do not need the same capacity as you might need to decide whether you have this form of chemotherapy with that set of complicating factors, or that form of chemotherapy with this set of complicating factors. The capacity and the need to say, 'Do I live or die?', is actually simpler than that. It might be the biggest decision but the actual cognitive abilities you need to make that decision should not be elevated to the point where we disenfranchise anyone who shows any sign of any depression.

**Mr WHITELEY** - What about if somebody is experiencing early stages of depression because of the sudden news that you have six months? I asked the question: how long to kick in? They said it was not often depression as much as something else.

**Ms FORREST** - Sadness.

**Mr WHITELEY** - Sadness and grief and whatever. With the guy that travelled up from Broken Hill, the paper of which you were a part said afterwards that he did reveal some very prominent features of depression, yet there was no indication that he was pointed towards help. Why wasn't that person then treated for depression or pointed in the direction of people to help him care for that? He died of natural causes shortly after that -

**Dr NITSCHKE** - He died back at Broken Hill.

**Mr WHITELEY** - Was there any certification process or regulation in the act that the depression in that gentleman was not treatable?

**Dr NITSCHKE** - It is a sort of rhetorical question because he turned up in Darwin and wanted to use the legislation. He never got past step one on the flow chart, so he never even got to the point of looking for a psychiatrist; that was well down the path. He didn't even get to a person who was prepared to say that this man was terminally ill. I couldn't find a doctor in the Northern Territory prepared to walk into that man's hospital room and say, 'This man is dying.' The reason they wouldn't do it was that they didn't want to be involved in the legislation.

**Ms FORREST** - That's their right, isn't it?

**Dr NITSCHKE** - It is their right. There was an ill-defined threat out there that any doctor who participated in the use of this law, should that law subsequently be ruled illegal, might suffer some subsequent retrospective legal consequences, so support from the medical profession evaporated out of fear. Slowly, as more and more doctors started to realise that this was a hollow threat, they got on board so that by the time the last person used that law there was no shortage of doctors prepared to act. Max Bell, unfortunately, happened to be first but he never got to the stage of a psychiatric assessment.

**Mr WHITELEY** - That's one case but in the other case with Ms Wild, who died after ROTI was repealed by Kevin Andrews's bill, consequential investigations revealed that there were significant issues to do with her mental and physical exhaustion. I think her record said that she was distressed and suicidal. There was a documentary or something made from that.

**Dr NITSCHKE** - Yes.

**Mr WHITELEY** - I recall seeing it, of which you were a part.

**Dr NITSCHKE** - Yes.

**Mr WHITELEY** - This was not a case similar to the one before where you didn't even get past first base; this woman was well past first base. Why didn't you or others that were supporting her recommend that she get some treatment for her depression, which was obvious through her GP records?

**Dr NITSCHKE** - The psychiatrist who reviewed her said that in his assessment she was quite capable of giving consent. She was able to satisfy the criteria of being able to make such a decision. The psychiatrist didn't see there was any necessary point in taking that any further.

**Mr WHITELEY** - So he acknowledged that she was depressed, suicidal?

**Dr NITSCHKE** - Well, suicidal in the sense that she was asking for help to die. I guess that makes it suicidal almost by definition.

**Mr WHITELEY** - Mentally and physically exhausted?

**Dr NITSCHKE** - But still able to give an informed consent. That was his professional opinion, not mine.

**Mr WHITELEY** - I suppose this gets to where we were this afternoon. Even though it is informed consent, informed consent in the environment of what state of mind?

**Dr NITSCHKE** - He believed that she had the capacity to make such a decision and was prepared to authorise her effective use of that act. There would have been other psychiatrists, no doubt, who would disagree, but he was not a psychiatrist in any way who had any doubts about his qualifications. He was a person who took the task very seriously, assessed in great detail and he came up with that conclusion. To my mind, I agreed with him.

**Mr WHITELEY** - So your personal view is that, even though someone may very well fit that persona, if there was any chance that they were able to make a competent decision, even in the midst of their exhaustion - physical, mental or otherwise - that still should be their choice?

**Dr NITSCHKE** - I think if it's assessed that they are able, they have the capacity to make such a decision, then to come along and frustrate and thwart them by telling them that they need to go down these other paths -

**Mr WHITELEY** - I hear what you're saying on that. I don't necessarily agree but I hear what you're saying.

**Dr NITSCHKE** - That's my answer to that.

**Mrs BUTLER** - I am interested in your comment about the gate-keeping role of the medical profession. You say that final adjudication on eligibility should not be made by the medical profession. I'm interested in who you think should make those final decisions and what sort of ethical stance those people would have?

**Dr NITSCHKE** - It's a difficult one. I don't have any easy answers to that. The medical professionals that are currently involved in signing off on this need to submit their reports. The final decision-making, though, shouldn't be left to the doctors. The way it is currently worded and the way it's being worded in the legislation being considered here, those signing off on each person's case by the doctors will be an essential step so that when the doctor signs a bit of paper saying that this person satisfies this or satisfies that they are effectively then and perhaps will see themselves as authorising that person's death, and that will cause them a degree of concern and alarm. It certainly caused doctors concern and alarm in the Northern Territory.

What might be a way around that if we do go down this path of trying to set up the myriad of conditions when a person can be eligible to get help to die, is that when the doctor's opinions are sought and the reports are made, those reports simply go in for some final assessment by a non-medical person - someone such as a judge or a magistrate, or someone from a different profession altogether. I just don't think that the person who makes the assessment should be ultimately be the one who then knows that those assessments are the key which allows the person forward.

**Mrs BUTLER** - You would rather see that in the hands of one person than a committee?

**Dr NITSCHKE** - A committee, possibly. A committee of peers, or even a jury. There are a lot of proposals out there and there are problems with the medical profession with this legislation.

**Ms FORREST** - What I'm hearing you say, Dr Nitschke, is that effectively you don't think this bill will work.

**Dr NITSCHKE** - I think it will work.

**Ms FORREST** - But you just said that the doctor is the gatekeeper, that the bill is very simple; it absolves the medical profession from the Criminal Code.

**Dr NITSCHKE** - Yes.

**Ms FORREST** - That is, it will give an exemption from the Criminal Code for them to participate in this process after jumping through a number of hoops and barriers.

**Dr NITSCHKE** - Yes.

**Ms FORREST** - So, you are saying that that's been a problem in the Northern Territory -

**Dr NITSCHKE** - Yes.

**Ms FORREST** - and now you're saying it's going to work.

**Dr NITSCHKE** - Well, look, it was a problem in the Northern Territory and the bill in the Northern Territory worked. I saw the Northern Territory experiment as a success. It was the world's first. I'm not suggesting it was perfect. I think it could be better. I suggest this bill will work too. There will be an awful lot of suffering Tasmanians who are helped by what they will see as - and I would agree - compassionate legislation, should you pass this bill. I'm not saying it couldn't be better though.

**Ms FORREST** - Do you think there would be an awful lot of people out there suffering that won't be helped by it?

**Dr NITSCHKE** - Yes. There will be an awful lot of people who will not qualify.

**Ms FORREST** - Many more than will be helped by it?

**Dr NITSCHKE** - Yes. You've been saying that. I've been listening to what people are saying. That's true; this legislation is only going to help a very small group of people but they are a very needy group of people.

**Ms FORREST** - There is also a very needy group of people out there that this bill won't go anywhere near.

**Dr NITSCHKE** - Yes, you're right.

**Ms FORREST** - So, what about those people? Is this bill discriminatory in that way?

**Dr NITSCHKE** - Yes, but let's face it; what we have now is even worse. This goes in the right direction.

**Ms O'CONNOR** - Dr Nitschke, you have dealt in close interpersonal circumstances with people who wish to die because they're terminally ill. Could you talk to us about - and obviously you can't make a sweeping generalisation here - about the state of mind of sufferers once they are at the point where they're seeking that sort of help. It has been put to us by the Australian Christian lobby, for example, and others who have made submissions, that anyone who wishes to die is in an abnormal state of mind and, therefore, more vulnerable.

**Dr NITSCHKE** -Yes, I know. We hear that a lot and I've read some of the earlier information and testaments you've received. By and large, the people that come along and talk to me in this situation are people that are increasingly desperate; they're fearful that people won't help them; they're often showing signs of depression and anxiety associated with the fear that people won't help them. Desperate people do increasingly desperate things. They're people who would love to know that out there, there was a safety net like this piece of legislation would provide. The idea that they can't, in any rational way, consider the end of their life, to them is ludicrous, to me is ludicrous. I find it offensive to have this argument that anyone who wants to end their life must be suffering some form of psychiatric, perhaps as-yet-undiagnosed illness, possibly depression, that we just haven't got on top of yet; that we've just got to look harder, find the disease, fix the disease and then they will want to live. I find myself having to rebut those sorts of statements every day of my life and they are common statements, but that's not the way I see the people who come to my clinics.

**Ms O'CONNOR** - In your experience with the people who accessed the scheme in the Northern Territory for the short time that the legislation was available, did you notice a change in the way they felt and expressed themselves once they realised that help would be provided? Could you talk about that a bit more please?

**Dr NITSCHKE** - Yes. It's already been described here in the Oregon experience. When people know when they leave the Oregon experience with their drugs in their hand or when, in the Northern Territory, they got the four signatures, as Bob Dent did, there is an immense weight taken off their minds. You can almost see them lift. I see it also today when people get their own little personal bottle of Nembutal. They just stop worrying. They have it in the cupboard locked away, they have their own personal way out of here. We have so much anecdotal evidence, but I am sure I will never able to prove it, that people who have that assurance live longer. They are happier, they know the legislation is in place, they do not have to worry about that any more and that takes one of the biggest loads off their mind. They get back to getting what limited joy they can get out of what is left of their lives. So I think they live longer with the knowledge that there is something like this in the form of a safety net out there.

**Ms O'CONNOR** - We heard evidence this morning from an ethicist who talked about the profound effect, if you like, on a medical practitioner who is in that position where they are assisting someone to die. It was put to us that that is a profoundly negative effect. Could you elaborate on that?

**Dr NITSCHKE** - Well, it is not much fun. It is the most stressful time of my life, going around to a person's place to help them die. I fought hard for their right. I believe passionately in their right but then of course it was crunch time with the law passing. Bob Dent said, 'Come around on Sunday; I will die on Sunday'. I knew this person. I liked him. He was not my best friend but I liked him and he says, 'Come around on Sunday, have dinner and I will die at 2 p.m.' It is an exceedingly hard thing to do. It was the reason I built a machine that allowed him to press a button because I did not want to sit there and give him the lethal injection that he asked me to give. The machine gave the injection and I sat over there on the other side of the room and watched it.

Everything is going through your mind. The difficulty, that last meal, what do you talk about, it has elements of an execution. There are things churning around. I found my shirt soaked in sweat, I could not eat my lunch and people said it was because you knew you were breaking some fundamental law. The problem with it was that I was fearful that things would go wrong. There was so much expectation heaped on one individual, and I was by myself.

In the legislation you are looking here you are talking about the prescription of drugs, and that takes away a lot of the anxiety, but the crippling anxiety I found, that almost rendered me in a state of paralysis, was the fear that because I was by myself things would go wrong.

**Ms FORREST** - Did it get easier?

**Dr NITSCHKE** - Not really. What got easier was the realisation that if the law persisted then other doctors were coming along. It was easier to get the qualification process and sooner or later I could just drop out of the picture. The only reason I went so hard at this was that, having worked hard to get the law through and having the College of Physicians ring me up and say you have got your law but it is never going to work, I thought I would show them. This is a law that can work, so I worked hard to make it work, but my plan was to just get out of it. You would not want to do this. You do not become the euthanasia provider for the Northern Territory. You are the doctor for the patient and there are not many of them. It has to get going. Those pathways have to be put in place and then it will be the doctor of the patient who steps forward.

**Ms O'CONNOR** - What do you see as the role of the sufferer's family in this equation.

**Dr NITSCHKE** - Yes, I heard that comment. I am sceptical about that. I can see what they are saying - this was the psychiatric presentation today - that you cannot assess a person's capacity unless you have significant input from the family.

**Mr WHITELEY** - Corroborative.

**Dr NITSCHKE** - Yes, and I can see that. I can see their argument there. However, many people's families are put into a deep feeling of ambiguity about the decision of their terminally ill relative to take this course. If they had any ability to frustrate and thwart any role in doing that, then that could well lead to more problems than it solved. In other words, giving some sort of formal input by such groups I think would be dangerous.

**Ms O'CONNOR** - So they are making a life-and-death decision at some level for the sufferer.

**Dr NITSCHKE** - Yes, and I would be wary about that. It should be clear that the only person making this decision is the individual. If they cannot make it, they have missed the boat.

**Ms FORREST** - The psychiatrists in front of us were suggesting that people could hold themselves together well and completely baffle us. I know of a lawyer who has been completely baffled and had the wool pulled over his eyes by a particular client who was saying, 'I'm confident mate, I'm right, I've got it all together', but when the family were consulted and when his doctor was consulted, it was found that he was really quite incapable of managing his own affairs. Some of these people are very clever and intelligent. Unless there is some corroborating evidence, then surely mistakes could be made.

**Dr NITSCHKE** - Yes, I can see it is a problem. Having said that, the thing that most upset the patients who used the Northern Territory laws was the psychiatric assessment. They dreaded it; they feared it. They knew they were dying. You'd have to be blind not to know that they were dying. They knew that they were going to have people who would say to them, ultimately, that they were dying, but whether they had capacity and whether or not the psychiatrist would sign off on the papers was something that filled them with fear. The third person who used that law put off his psychiatric assessment every week for about a month or six weeks. Every time the appointment was arranged he put it off and said, 'I'm too miserable, I'm too sad; he'll say I'm depressed'. So he wouldn't do it; 'I'll wait until next week when I cheer up'. Meanwhile his stomach cancer was worsening and we left it to the day he died. On the day he died we went to his apartment where he was to die - because you weren't allowed to die in hospital. One of the quaint things of the Northern Territory law was that you had to die in your own home. We were taking him out of that hospital where he'd been for two months, via the psychiatrist rooms. He knew he had to get a signature but he was afraid that he wouldn't be able to hold it together in the way that you're suggesting some might be able to. Maybe if he had talked to his family that would have been a way of taking away some of those concerns, but it's not an easy question about whether the family should be involved. Perhaps they might give an opinion, but the idea that they should have any sort of formal status or formal ability to frustrate a patient's wishes would be dangerous.

**Mr WHITELEY** - Was that the case where the psychiatrist's consultation was 20 minutes in duration?

**Dr NITSCHKE** - Yes, it was.

**Mr WHITELEY** - Claims were made that in certain cases such as that one that technically and legally that was a breach of the Northern Territory act. It wasn't truly a consult, it was a convenient consult. Basically you took him home via the psychiatrist's office for a 20-minute consult. How is that not a breach? Of course, you might not agree with it because you're actually saying if you wrote this bill it wouldn't have the psychiatrist involved at all.

**Dr NITSCHKE** - Wouldn't have it at all, yes. The psychiatrist, of course, was of the opinion that he did the job properly. Some people say he couldn't possibly do so in 20 minutes. There were certain humanitarian concerns. This was a man who was just about dying in the wheelchair and we held him in the wheelchair there while this consult went on. He should have done it two months earlier but he refused to do it two months earlier because he thought he might fail it, so he left it to the last minute when he was just about dead. Then, perhaps you could say that this compassionate psychiatrist gave a rather cursory assessment of his capacity. So maybe it was a breach but it was a breach that was motivated, I would say, by compassion.

**Mr WHITELEY** - Is this the one where you talk about taking him home to a musty house?

**Dr NITSCHKE** - Yes.

**Mr WHITELEY** - And you said that you had to hunt for sheets to cover the mattress?

**Dr NITSCHKE** - Yes. That was a bit quaint.

**Mr WHITELEY** - You later spoke of your sadness over the man's loneliness and isolation as you administered -

**Dr NITSCHKE** - Yes, that's true. I might also point out that this does come up in our findings in the paper. Three were socially isolated. Earlier people that have given evidence here suggested that social isolation needs to be addressed before a person can be considered for help, but there's an awful lot of socially isolated dying people. The question is, how important is the social isolation to their ability to make such a decision? If you are going to say, 'Well, first of all, we'll stop them being socially isolated and see if they still want to die', that's just not possible. They are socially isolated people; they've been like that for a long time and he was that archetypal socially isolated person who had no family, but did that mean he didn't want to die? No. You can't suddenly make him socially un-isolated. That was the way he was.

**Mr GAFFNEY** - We've heard today some suggestions from parliamentary counsel, coroners and others about some suggested improvements to the current piece of legislation. They recognised that it's a catch-22. In your experience, some legislation is better than no legislation?

**Dr NITSCHKE** - Absolutely.

**Mr GAFFNEY** - Have groups connected with your philosophy looked at the bill's intent and suggested any improvements that at this stage could be considered, other than chunks of it?

**Dr NITSCHKE** - I am fearful that nothing will go through. A bill with all the problems we had in the Northern Territory is so much better than a situation where there is no legislation out there. I would be very upset if this particular piece of legislation was to falter. If it were to falter simply because we think we can do better than this, well okay let us do better, but let us not use that as a reason for doing nothing. That is unfortunately what often happens. They say this is not quite perfect so let us make sure that we do not go down this path. You can identify of lot of things here that could be better but the risk there is that you will end up with nothing. If you end up with nothing you will leave in place what I often describe as a jungle out there.

**Mr WHITELEY** - We have taken evidence, and this is the case on any moral or social issue, in relation to the concept of slippery slopes. Your views are clear. You could hardly say you have hidden them under a bushel. You are saying this would be better than nothing, yet your comments on the record would indicate that for those who fear a slippery slope this bill is probably too tight. For example, you just said a moment ago that if you had your way psychiatrists would not be involved at all.

You gave an interview in relation to some of these matters to do with depression and stuff to the *National Review* some time ago where you started to talk about your personal view. I know it is not linked to this bill but this is in the context of the slippery slope. You said that we need to provide the knowledge, training or recourse necessary to anyone who wants it, including the depressed, the elderly, bereaved and the troubled teen. What do you mean by that?

**Dr NITSCHKE** - That is a question I get asked a lot. Usually I come prepared with the complete question and the complete answer from the *National Review* interview because there is a context for that question and answer. It is quite a detailed answer, and that is one sentence which is invariably lifted out. I am quite happy to provide the full context of that. These were my personal views about whether every rational adult has a right to access a peaceful death. That is what I said, basically, that rational adults have a right to a peaceful death. It turns out that you can be an adult or a teenager and it turns out that you can be rational and troubled. If you start looking at that then you can end up with that sort of situation. I think there are probably better ways to put it than the way I put in that unfortunate interview in 2001, and I have been answering that question ever since, nevertheless that is my personal position here. That is not, of course, what we are doing here. You have asked about slippery slopes -

**Mr WHITELEY** - That is in the context of the slippery slope where some would say, 'Well for goodness sake, let us not pass this because people like Nitschke will have us sliding down this path'. We had evidence from the Royal College of Nurses and one of those ladies gave evidence that she has never seen a person more distressed than a young girl who had a broken relationship - very troubled, a lot of suffering and distress. She bashed her head against the wall and injured her head.

**Dr NITSCHKE** - Well she would not get access to your proposed legislation.

**Mr WHITELEY** - But under legislation in an ideal world in the slippery-slope context she would.

**Dr NITSCHKE** - I think the best answer to slippery slope is this. There is not much evidence of it occurring in places where it has been monitored for a long period of time. We look at Oregon and Holland and the like and there is not much evidence of a slippery slope. You can never satisfy people. Maybe there is a slippery slope, but surely the answer is to look closely at what you have, wait for a period and then look at closely what you come to. Compare the two and see whether there is a slope. If you have passed legislation here in the Tasmanian Parliament, look at what happens in a few years time and see whether there is a slope. It is not locked in stone. People by and large have seen an evolution of thinking on issues such as abortion with time, and society changes its position. If in five years time the people of Tasmania look closely at the legislation which you courageously passed in 2009 and are happy with the way that slope has progressed - be it up or down, but it has changed and evolved - then leave it there. If you are not happy, put it through Parliament and get rid of it. You can change laws as you can make them.

The idea is usually that there might be a slope so we should do nothing. We can't take a risk, therefore we should leave what we've got, but what you've got there now is a jungle. What you've got there now is unjust and it's inequitable. People get the drugs if they know what they're doing. It's not the case, as a person here said earlier, that any fool on the Internet in five minutes can work out how to die. It is not that easy. You need to know what you're doing and people who know what they're doing do all right and people who have money do all right. You are leaving in place something which is obscene. To tackle it with something like this progressive legislation, albeit with its faults, I see as a courageous and civilising way to go.

**Mr WHITELEY** - On palliative care and your exposure to palliative care over the last years, do you have any training in that?

**Dr NITSCHKE** - No. I had a long discussion with Roger Hunt, whom I think you have talked to, about doing formal qualifications in palliative care. By that stage we decided that I was too enmeshed in what now had become a fight to the death on the politics of this issue, and also the fact that I've been exposed to a lot of it now. So, no, I haven't had the time, in a sense, to take on the formal qualifications in palliative care. But I watch that profession with a great deal of interest. I think it is a necessary and essential part of modern medicine and I get annoyed when people try to set up some artificial divide between palliative care and the choice to die. By and large, the people I see want the best palliative care but they also want to know that, if it fails, they have this other option. There should be no conflict between those two fields.

**CHAIR** - Dr Nitschke, we appreciate very much the trouble you've taken on something you feel very passionate about and you are a great campaigner for it. We thank you very much for taking the trouble to come all the way from Darwin to give evidence today.

**Dr NITSCHKE** - Thank you.

**THE WITNESS WITHDREW.**