

**THE LEGISLATIVE COUNCIL SELECT COMMITTEE ON ORGAN DONATION
MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART, ON
THURSDAY 14 FEBRUARY 2008.**

Dr MEGAN ALESSANDRINI, UNIVERSITY OF TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Wilkinson) - Megan, thanks for coming along. We understand you are the expert and that you wrote a paper on it for your doctoral thesis. Is that right?

Dr ALESSANDRINI - No, it is related to my doctoral thesis. The doctoral thesis area is non-government organisations and I have gone on and done further research with the Red Cross Blood Service.

CHAIR - As you know, we are looking into organ donation and the best way forward. I must admit I came into it with the view - and this is just my personal view - that there may well be an opt-out system available. We have received evidence from a number of people to say that that most probably would not be the way to go, so we have been learning as we have been going along as well. I will throw it over to you and let you say what you want to in relation to it and then we will open it up for questions.

Dr ALESSANDRINI - I have prepared some notes for you. This is the first time that I have had the opportunity to speak to a committee of this type. I would like to thank you for the opportunity to speak to this select committee on this topic. I hope that I am able to provide you with some valuable information.

I have a public sector background in the Commonwealth Public Service of 21 years before I did my doctoral studies at the University of Tasmania, with Honours and a PhD in public policy, so I do have some credentials in this area. My research area is non-government organisations and their relationship with institutions of government, especially in the delivery of human services. My interest in organ and tissue donation and transplantation arose from previous research that I have done into blood donation in Australia. The Australian Red Cross Blood Service LifeGift organisation is a coordinator of organ and tissue donation in the ACT, New South Wales, Victoria and Tasmania. Other States - and you are probably well aware of this - have other arrangements in place; State government funded and administered agencies that coordinate these activities.

Through my research into blood donation, predominantly in Victoria, I became aware of and interested in the policy issues surrounding organ and tissue donation. The paper, which I believe you have copies of, the politics of organ donation, 'Chasing a Rainbow', is the result of a comparatively small nationwide telephone survey that had some funding to run and was conducted in 2006. On the third page of that paper there are some international comparisons, which I hasten to say is a fairly dangerous thing to do because definitions of what constitutes a donation or a successful transplantation, definitions of death, what is included in the statistics, vary enormously internationally. It is a very sensitive area, but I am persuaded that these statistics do give us a reasonably clear picture certainly of Australia's quite low rate of success in this area.

It is important to think about the Spanish model, what happens there and why that works so well. The evidence is that it is dependent enormously on coordination and on relatively small teams of people working together with a clear goal in mind. I think I have mentioned in the paper that some incentives are paid for when they have successes. What constitutes a success is that a family is contacted, they are made aware of their options and win, lose or draw it is still regarded as a success if that process is gone through, whether a transplantation results or not. There is certainly a great deal to be learnt from the Spanish model, I think.

CHAIR - From what they are saying a 'success' is if they just contact the family and go through the process with the family, even though that family might say they do not wish to allow the organs to be donated?

Dr ALESSANDRINI - Yes. Obviously the ideal outcome is when a transplantation does result and there are organs and tissues donated. There are also circumstances in which this is not going to be agreeable to the family involved.

To move on to the survey, 1 000 individuals were interviewed nationally. Many more were contacted and declined to participate in the survey. It is a very sensitive issue and many people were just not willing to discuss it on the telephone. We have all had those calls at tea time. It is the time when people least want to talk, I suppose.

The circle was stratified so there were same proportions for the general population for gender and age, but not for resident State, otherwise we would not have been able to know anything about Tasmania because the numbers would have been so small that it would have been pretty meaningless. This meant that the medical data was able to be collected for smaller States.

About the findings: it is crucial at this point to say that the results recorded statistically are what is regarded as trends; they are not concrete, the samples are very small but they are indications of areas where further research could certainly be done. That is my safety clause, I suppose. So they are trends rather than strong causal links because of the limited size of the sample and the simplistic nature of the questions asked. Also I suppose we need to take into account the high number of people who refused to participate so that is a whole lot of stuff that we are not uncovering about what is really going on in people's attitudes to this topic.

CHAIR - Are you able to give us the percentage of people who did not want to participate in the survey?

Dr ALESSANDRINI - I think there was - and it may even be in the paper - I can confirm this -

Ms FORREST - The response rate was 22.6 per cent.

Dr ALESSANDRINI - Okay, you have found it. I was going to say 30 per cent, but 22.6 per cent, so that is really very low as you usually get around 50 to 60 per cent. It was anticipated by the people conducting the survey that they would strike this kind of resistance.

Ms FORREST - Can I confirm that there were 226 people who actually -

Dr ALESSANDRINI - No, there were 1 000 people. They kept going until they got 1 000.

Ms FORREST - So they got 1 000 people.

Dr ALESSANDRINI - Yes, that would have been a little worrying. They persevered.

The questions were fairly simplistic but that is necessary for a telephone survey if you are going to get anything from people. The research can be regarded as preliminary and providing an indication of directions that further research will take.

A bit about the findings: many claimed that they had registered as donors and it was not really possible to explore that in any depth other than to say that a great number of people had said that they had done it with their driver's licences so there are still problems with people not understanding the process.

CHAIR - There are still people out there who think that, because they ticked their driver's licence five or six years ago or whenever it was, they are still on the list.

Dr ALESSANDRINI - Yes.

The reasons that people gave for wanting to be registered as organ donors: 66 per cent said to help someone; 4 per cent knew a recipient or potential recipient and, in terms of those who had registered, income was not found to be a factor, but more on that later because it does intervene later. More of the registrants had children than did not.

Interviewee family members: 42.7 per cent of those who responded were aware of relatives who were registered donors; 29.9 per cent were aware that relatives definitely were not donors. In terms of the age groups, the four age groups in the 25 to 69 age range had the highest rates with a sort of a plateauing: 25 to 34, 63.3 per cent; 35 to 44, 55 per cent, so it goes up and down there; 45 to 54, 60.2 per cent and then it starts to tail off in the 55 to 69 age group and it drops down to 52.6 per cent. It could be speculated that that is related to health issues/health reasons.

CHAIR - Were there any studies done on that as to why that happens at that age group? Is it people thinking 'My organs are too old and they will not want them any more' or is it because they are thinking, 'If there is an after life I want to there fully intact'? Did they give any reasons?

Dr ALESSANDRINI - Actually, yes. That comes up later but they did give reasons such as they did not think their bodies would be suitable or that they were in ill health and another response, when talking about whether they would change their minds, people said if their health improved they would possibly change their minds. It's an interesting way to look at things.

Ms FORREST - The body image stuff was interesting too.

Dr ALESSANDRINI - Yes. It is kind of peripheral, but it would be great to explore that a lot further.

Looking at the marital household status, couples with children, as I have said, had a higher percentage of registered donors. The rate for families with children under 16 was 58.7 per cent. That didn't vary at all. For families with children over 16 it was around about the same number. Married with no children at home it was 57.8 per cent, so that stays stable. For people who are separated or divorced it was 69.1 per cent. It would appear that a rational understanding of the benefits out of context, when you're not going through these sorts of traumatic events, is not a problem. So 48.8 per cent of those not registered said that they would consider becoming a donor and 29.4 per cent were not very likely or very unlikely to reconsider under any circumstances.

We will look now at the reasons that people don't register. Again, I want to remind you that the numbers are very low. If you have a look at table 5 - we are talking about preliminary research. This is preliminary research that just gives us some indications of where research could go in the future - 48 per cent, or 112 individuals, said that there were no circumstances that would change their minds. None at all, they couldn't envisage a family situation or anything that would make them change their mind. Twenty-nine per cent said that they would consider changing their mind if it involved the needs of a family member.

Ms FORREST - I thought that was fairly low, that only one-third of people would consider changing their mind in such circumstances. To think that two-thirds of people, even in the face of losing a child, would still say, 'No, I wouldn't do it'. I find that quite interesting. It wasn't delved into any further than that?

Dr ALESSANDRINI - No. Unfortunately, with a telephone survey, it is a 'tick-the-box-and-move-on' situation. As you say, these are areas where there is really great potential to find out a lot more about what people are thinking. I suppose you could envisage situations where, say, if there were religious or health reasons and they didn't want to pass on something unpleasant. It is difficult to say.

Mrs RATTRAY-WAGNER - Even the financial implications of not being able to earn an income. That obviously would have to be factored into people's lifestyles.

Dr ALESSANDRINI - That's true.

For 21.4 per cent there were assorted other reasons. Here we start to see some indication of possibly a link with income level. Income level is apparently a factor influencing the reasons that non-donors make that choice, as with those who would be willing to donate and marital family status is a factor also, although single people were more willing to reconsider.

On the basis of the evidence from this research, I have gone through and made some notes on each of the terms of reference. As to the first term of reference, it is not possible from this research to distinguish between Tasmanians and others responding to this survey, but I can say that there are certainly no glaring differences between Tasmanians and people from other States otherwise that would have been evident from the data. There is nothing outstandingly different about Tasmania. It is apparent

however that this is a national problem that may well benefit from a national approach to the solution. Tasmania may well have a role as a site for a pilot of some kind. I think that has been done successfully with other social medical areas such as the current genetic mapping they are doing. As I am sure the committee's aware, there has been a recent pilot collaborative project conducted by Australians Donate that has reported success. That is a possible avenue that could be pursued.

It is apparent from the data that among those responding to my survey there is a widespread recognition that there is a system of registration for organ and tissue donation, although from this research it is not possible to say anything conclusive about how well this is understood, other than anecdotally. There are a lot of people who did say the driver's licence thing.

On the second term of reference, Tasmania is under the auspices of LifeGift, a part of the Australian Red Cross Blood Service Victoria - the Victoria-Tasmania region. In general, the approach taken in Australia has been quite a delicate one. As with blood donation, in many instances it has been something that has been handed to non-government organisations to manage so there is potential for inconsistencies between States and institutions that can arise where you are outsourcing those sorts of services. Given the success of the Spanish system, it seems likely that there would be benefit in exploring these practices elsewhere. While this is covered briefly in my paper, there is certainly scope for much more detailed research in this area.

As to the third term of reference, my research does not clearly identify a direct causal link, for reasons I need to keep reiterating: the size of the sample and the nature of the survey. But if we consider table 12, which deals with income levels of non-donors and factors that would cause them to change their mind, it is clear that those on higher incomes stated that they would be more likely to be persuaded to change their mind than those on lower incomes. Forty-five per cent of those with incomes under \$75 000 would not consider changing their mind, versus 38 per cent over the \$75 000 income rate. As we know, Tasmania has more issues with low income levels than other States so there is a possible link there. While I have no clear data on education levels of donor registration, this is an area that would benefit from more research as Tasmania is also near the bottom of the table there. That is something to be borne in mind, I think.

As to the fourth term of reference, I am unable to comment on the impact of a family's wishes on the choices made by doctors about donation. It was not something that I was in a position to research but my survey did ask a hypothetical question about the impact of uncertainty or otherwise on individuals' wishes. If you look at table 13 it tells you a bit about that. These are multiple-response questions. These people are saying that if family members disagreed they would possibly still consider going ahead with the organ donation. If it were the wish of the deceased person, they would feel that they couldn't refuse. They would feel concerned and reluctant to go ahead if they hadn't discussed it with the deceased person, but they may still consider it. These are issues that are problems. Other people were saying that under no circumstances would they do it. It was 15 people, a mere 2 per cent, but they were still saying that under no circumstances would they consider it in that hypothetical situation. When asked to identify whether they would consent to organ donation from a next-of-kin and, if so, under what circumstances, 2 per cent said never, there would not be a situation. There is a first response rate of 15.9 per cent of people who, even though they felt some reluctance,

would feel that they could not refuse and it would depend on the circumstances that 5.4 per cent first response figure.

A further question revealed that many people thought that they would be influenced by certain factors. If we have a look at table 14 - and this is interesting; this was the first response of 358 of the respondents - they said the wishes of the deceased would certainly be a factor, the advice of a doctor and, considerably less so, the advice of a nurse.

Ms FORREST - In another table you talk about one of the reasons people are reluctant is that they are mistrusting of the system and they mistrust the doctor, so it is a bit of a contradiction, isn't it?

Dr ALESSANDRINI - Yes, but I suppose that is human nature, that we are paradoxical at times. At a personal level we may trust our GP and trust someone that we have built up a relationship with, whereas you may feel in general terms that we would have some misgivings about it.

Ms FORREST - You do not come across your intensivists very often as a general rule.

Dr ALESSANDRINI - No, that is true.

Ms FORREST - If you cannot put up a trusting relationship maybe that is the difference because that person is only really caring for someone in those circumstances where it is pretty stressful whether they are living or not going to be living, unless you know them outside the setting, I guess.

Dr ALESSANDRINI - Which does raise some issues for this team approach where you have counsellors involved, social workers, people who may have been through the system already, just forming a team and working to get some positive results.

Ms FORREST - When you commented about the team approach, that was one of the driving factors for success in the Spanish model, which I think has been taken up partly in South Australia. Because Tasmania is so small and we have so few opportunities for organ donation to occur, do you think that a team is going to work here and is it sustainable financially? We have had evidence that we need to have a medical coordinator as well as an organ donation coordinator who may be a nurse with some experience and maybe we need two positions, one in the north and one in the south, and then you add in the social workers and the other people. Is that a realistic model to even consider for Tasmania?

Dr ALESSANDRINI - I would not be willing to comment on the financial side of it other than to say that there is considerable evidence that there are enormous cost savings to the health system from a successful transplantation. Maybe in the short term there would be costs but there are enormous savings from a successful transplantation when people can resume productive lives requiring so much less medical support and have a much greater quality of life.

Ms FORREST - Do you think there is a need for a medical coordinator as well as an organ donation coordinator who is not necessarily an intensivist or someone of that level?

Dr ALESSANDRINI - I guess we are getting into the area of my opinion here and on the basis of research that I have done I do not feel able to make any conclusive comments on that. I guess I could say that I think part of the reason that the Spanish model works is that it is a team, it is not a hierarchically structured thing. There are teams of people who are really gung-ho on this area and it is their vocation and they put enormous energy into that. That is all I could say on that.

Ms FORREST - So should the team be involved in education of the public as well? It is often through a lack of information or knowledge that people have fears.

Dr ALESSANDRINI - That's true.

Ms FORREST - A team approach would help to address some of that as well. I am just trying to look at what we should be looking at or whether one person could do the job. I guess I am asking for an opinion. Have you seen other models or looked at other models that have worked with fewer people or does the team seem to be the way to go?

Dr ALESSANDRINI - I think the team is the way to go, simply because of the range of skills that are needed. The other thing that is apparent is that where people feel some kind of personal connection they are much more likely to agree to be involved.

Ms FORREST - As part of the team, do you mean?

Dr ALESSANDRINI - No, I'm speaking about people willing to make donations. I pick up on this a bit in the paper. There is this idea that organ donation is portrayed as being normal, something that happens every day, don't worry about it, everything will be all right. That is a disjuncture with how people are feeling. They are likely to be feeling that they're making an enormous sacrifice and they need that to be recognised. They aren't necessarily comfortable with making this enormous sacrifice and it just going off into the ether to an anonymous stranger. Obviously it's not possible to make any connections, but research did indicate that where people had some indication of where the organ was going - to a grandmother who was awaiting the birth of her grandchild or to a young child who was beginning its life or to a young parent - where they had some indication of the reality that their sacrifice was going to be worthwhile - they felt more comfortable.

Ms FORREST - About the decision-making process, they wouldn't be informed of that, would they, because it's not until the tissue typing and finding a suitable recipient that you can inform them? Or are you talking more generically about the type of person it is going to rather than the specific?

Dr ALESSANDRINI - I think what has been done in some situations is the specifics, not naming anyone. It is really not appropriate to do that and there are lots of legal barriers to that. It has been suggested that where people have an idea of where it is going they will feel more comfortable about it. Additionally it has been shown that some of these high-profile campaigns just haven't really changed attitudes and behaviours at all. Kerry Packer, David Hookes and these sorts of campaigns have not had the impact that has been hoped for, whereas something like Zaidee's Rainbow, which is taking a more long-term approach, gradually drilling into people's subconscious, talking about sacrifices and real situations and the enormous positive benefits that have been made, has

a much more sustained impact on people, rather than brand-of-toothpaste kind of approach where there is a marketing campaign of some sort.

CHAIR - A lot of people still don't seem to understand it is impossible to recover from brain death. The David Hookes Foundation endeavours to say in their brochures that it is impossible to recover from brain death, but when it comes to their loved one, a number of people cite these miracles that you hear about - whether they are miracles or not, who knows -

Dr ALESSANDRINI - The urban myths about people waking from a coma.

CHAIR - suddenly recovering after years in a coma.

Ms FORREST - They are not brain dead, though.

CHAIR - That is right.

Do you think it has a lot to do with education? I know with the meetings we have had with a number of different people it seems that this education process needs to be drilled into the community for the community to realise that if there is, unfortunately, brain death they are not going to recover and therefore you can move on. But if you don't really accept that, you aren't willing to donate the organs.

Dr ALESSANDRINI - That needs to be done at a time where there is able to be a rational acceptance of that because, if you're trying to explain that to someone when they've just been through what is in most circumstances a traumatic, unexpected bereavement for transplantation to be possible, you are going to have more difficulty persuading people at that time.

Mr HARRISS - Megan, getting the message out and getting people to change their views will always be a challenge, as you have identified. Professor Bob Jones from Melbourne suggested to us that perhaps we should approach it from a different angle. In any interview process we should probably ask people whether they would like to be an organ recipient rather than an organ donor. You can guarantee that everyone of us would like to be an organ recipient in the time of some medical crisis. From there you can go in a slightly different direction. Do you have an immediate response to that? It is an opinion, I guess.

Dr ALESSANDRINI - Intuitively it makes sense, doesn't it?

Mr HARRISS - Maybe you could build on that and take another direction. Maybe this committee could make recommendations about that as the launching pad, something to build on. Marketing strategy seems a bit of a strange term where you are talking about such a sensitive issue but there is a need to get the message across that in the end this saves lives and a heck of a lot of money compared with the old system.

Dr ALESSANDRINI - That is true. I think it is one of these issues that could have emphasis - and I am veering off into opinion here - in the sorts of values and pseudo religious-type education that is being done in schools, the personal and social development, so that young people have an open mind about it and that they have considered these issues so

that is not coming to them from left field, that everyone has a chance to think about these things in the same way that they think about religious issues or the range of things that are covered in personal and social development. While they might say, 'Oh yuck no, I wouldn't like to be cut up', if you opened with that other scenario it is most definitely inviting people to think about it in a different way.

Mr HARRISS - One of the issues which we have confronted is the matter of the registers and their enforceability and the challenge that that is at the immediate time of the death. I just wonder why we could not develop a legally binding system so that if I, of my own choice, decide that I want to identify as an organ donor then clearly I should discuss this with my family but in the event that I do not, why cannot my wishes be legally enforced if there is a legally binding register? It is no different from a will. A will is an enforceable document so why can't my wishes be legally enforced? Maybe the committee could consider that at some stage. Do you have a view about that?

Dr ALESSANDRINI - I am not a lawyer, my expertise is more in the sociological area and I could envisage that there could be great social costs in the law being seen to override the wishes of a family in that situation.

Ms FORREST - The health and wellbeing of the survivors, because they have to continue living and living with the trauma of the death of the person, does perhaps need to be taken into consideration.

Mr HARRISS - Yes, it is not black and white.

Ms FORREST - Unfortunately, most things in life are not.

Dr ALESSANDRINI - Which is where you have your team of persuaders, people who can explain that there is a perfectly good reason, that actually George did sign up for this and it is clearly what he wished, so we should probably proceed. You just have to get the mixtures right with law and social perspectives.

CHAIR - Because what appears to be happening is that, even though a person may sign up to say that they are willing to be an organ donor, if the family do not agree with the medical fraternity who speak with the family, even though the wishes are that they want to be an organ donor the doctors do not normally do it because the family say that they do not want it to occur.

Ms FORREST - Litigation would be significant there.

CHAIR - Yes, and then there is the problem in relation to that as well that they say the best thing to do is for the person who is signing up to discuss it with the family. Often they do not discuss it with the family and as a result of that their wishes are not known. Again it is this education process that seems really to be a key in the whole issue.

Ms FORREST - Just coming back to that point that Paul raised a moment ago about Professor Jones when he spoke to us about asking people whether they would be willing to be a recipient rather than asking whether they would be willing to be a donor, I did a bit of my a research project with my teenage son and asked him initially whether he would be a donor. I am a donor and I wanted to talk about that, but his attitude was, 'I

don't know if I want to talk about that. I'm a bit young and I need mine at the moment'. I asked him to think about it. A week later I went back and said, 'If I needed an organ transplant urgently or one of your siblings did, would you want them to be a recipient or would you want to be a recipient yourself if you were that person?' and he said, 'Oh yes'. He said that he had thought about it and he would be happy to be a donor. I do not know whether he thought I was trying to coerce him or not but I watched his face carefully as I asked him both questions and he said, 'Of course'. Being a researcher, maybe that is a research area that could be handled simply in a telephone interview almost asking the question, although you cannot see people's faces over the telephone obviously - not that you can quantify their facial expressions either. Do you think that is a reasonable path for further research in Tasmania or in Australia as a whole?

Dr ALESSANDRINI - It sounds like a really good marketing tool.

Ms FORREST - Do you think we need to go straight into it without the research?

Dr ALESSANDRINI - Yes. It would seem that it is something that is likely to persuade people. It would be good to validate it with research but it would be a bit difficult to pursue it. Changing their attitudes as part of the research is -

Ms FORREST - Manipulative?

Dr ALESSANDRINI - A little bit manipulative, did you say that?

Ms FORREST - Yes.

Dr ALESSANDRINI - Just a little.

CHAIR - Certainly numbers were fairly small as well.

Ms FORREST - Extremely small and not necessarily anything to go on but I just thought it was interesting.

Megan, in your paper it says, 'Organ donation and transplantation in Australia is managed by a number of non-government charitable organisations and this appears to be a positive factor'. Do you think that people believe when it is out of government's hands it is better - I am not sure whether that is the right word - are people more willing to accept the information and advice from a non-government sector and if the Government were to take it over and drive it, do you think that would be negative and that is not something we should suggest?

Dr ALESSANDRINI - It seems that there is considerable mistrust first of all of business and also of government institutions, whereas with non-government organisations there is quite a high level of trust - and this is research in 2005 that was written up - and that makes some sense and it is a concern in Australia. Calvary hospital is now a business and it is not run by the church any longer, although it still has that sort of aura about it. According to the research, people are more likely to trust a charitable non-government organisation. They will not necessarily think that they are particularly efficient but they are more likely to trust them to do the right thing.

Ms FORREST - We had some evidence that organ donation in Australia is a bit like a cottage industry where you have lots of little organisations that are non-government organisations all doing their bit to promote it and to make it work essentially. Do you think that it needs more coordination and perhaps one overarching non-government organisation or is that going to end up looking like a big business and again perhaps undermine the confidence the public have in it or is it better to keep with the small cottage industry type of approach?

Dr ALESSANDRINI - I think that has been attempted with the Australians Donate organisation. It does a lot of data collection and it is a clearing house for that kind of thing. They have had a couple of initiatives. They do not seem to do a lot of research but they are a clearing house for research and coordination of services. I think in terms of how things happen medically it may be regarded as a cottage industry but I think it is fairly professionally handled and I do not think there are any real concerns there. I do not feel I need to comment any further on that, other than to say that there is much greater trust of the non-government sector. Australians Donate is apparently -

Ms FORREST - There is a collaborative as well.

Dr ALESSANDRINI - Yes, they have a collaborative project that came out of it, a pilot, but it is in its demise, I believe. It has been replaced by a cognate committee, I think they call it.

Ms FORREST - Someone asked me what a cognate committee was. I read some of those papers. I think the funding was running out and they were looking at replacing it with this cognate committee that was going to be more a government body.

Dr ALESSANDRINI - It has been described to me as a team of faceless bureaucrats by someone in the scene, but I have no particular view on that.

Ms FORREST - From what I have read that is the way it sounded that it was heading. If that is where it goes, into a bunch of faceless bureaucrats and essentially a part of government, do you think there is a risk of undermining the public confidence in the whole process, as opposed to Australians Donate, which is a totally independent area?

Dr ALESSANDRINI - It is difficult to say. I have not read the terms of reference for this group - I am not even sure if they are available - so it is difficult to say. If they are not intrusive, if it is just a simple bureaucratic exercise, it might make coordination a bit easier between the States because they have different arrangements. As you have pointed out, the South Australian experience has been quite a good one and that is a State government-run business.

CHAIR - The National Collaborative was going to bring down a report in December. We were told on 1 February that it was going to be about three to four weeks before they bring down their report. Do you believe it is imperative that Tasmania links in with the National Collaborative or, alternatively, let us say they do not bring it down in three to four weeks, should we go off on our own and say what we believe should occur? To me, it would seem wiser to endeavour, if we can, to link into the Commonwealth approach because it may mean in the end that there is going to be a better education process if we link in with them, as opposed to go it alone.

Dr ALESSANDRINI - I think with the National Collaborative exercise, by all reports, there have been some successes. I am not sure statistically how significant they are or socially. As you have pointed out, there has not been much available; it has all been fairly descriptive about what has happened. It has been a fairly important experiment, so I think you would be well advised to have a look at what is coming out of that group before deciding how to proceed. There are some good people involved with that. People from LifeGift were involved with it, for example. There is also some great research being done at Monash University in Melbourne.

CHAIR - If you were asked to set up a task force to create more awareness, to try to lift the numbers of people donating within Tasmania, what would you do?

Dr ALESSANDRINI - The first thing I would do is look at what has happened elsewhere and do a really intensive exploration about how these things have been handled elsewhere. Like it or not, there are strong similarities between our social arrangements and what has happened in other countries and I think there is much to be learnt. Academically, you look at what has been done first before you try to reinvent the wheel. Then I think you need to think in terms of long-term strategies rather than the short term and what is going to have a personal impact on people. I think everyone here today is aware that we have recently lost a very notable Tasmanian due to the lack of a transplantation opportunity and I think in the Tasmanian context that is a really personal connection for very many people. People felt a personal connection with this situation so it is something that could have a long-term impact; it could be used as a springboard to move on from.

I am reminded here of the work that I did with blood donation and one of the things that came out of that was there was a willingness to be a blood donor and to make that ongoing commitment and to keep going along and to keep monitoring your health as you need to do and not donate at certain times. It was about social connection, it was about feeling that you were part of the community, that you were a citizen. I suppose one of the interesting things was that there were very, very few Aboriginal blood donors. There is that idea of citizenship, of it being part of your identity as a citizen 'I'm on this committee, I do this, I donate to this charity, it is part of my identity and I'm a blood donor and this is what makes me connected in society'. I guess if that sort of identity, that engaging with society, engaging with your neighbour, being good friends, being a good family member, if that kind of notion could be developed in the same breath as being an organ donor it is just something that you do as a -

Ms FORREST - Like charity work almost.

Dr ALESSANDRINI - Yes or -

Ms FORREST - Volunteerism - that sort of approach.

Dr ALESSANDRINI - Yes. The idea is that you are volunteering and you are involved with this committee or that committee or that organisation. You are giving to them and it is a sacrifice but you are deriving great benefit as well, society benefits and you have a sense of connection. It is about community engagement, the social capital. That would be a direction to go. If you meant specifically, 'Who would I go out and head hunt and how

would I set it up?', I would think a lot about the principles of it first and what I was trying to do before I looked at the skillsets I would need and the profile.

CHAIR - Are you able to say whether you believe Tasmania is at a disadvantage because it does not have a coordinator which other States have? That coordinator is a person who could go around the State, whether you had one in the north or one in the south, whether you have one or two to deal with the whole of Tasmania would have to be looked at, but do you think we are disadvantaged at this stage by not having a coordinator?

Mrs RATTRAY-WAGNER - Slash educator.

Dr ALESSANDRINI - Certainly there would be great benefits from having someone in that coordination role. I am not sure how appropriate it would be to have in such a small geographical area that same person involved with the coordination of procurement and so on, but certainly there would be great benefits in increasing that educational role.

CHAIR - What about hospitals doing audits on it? In some hospitals around Australia they are having audits - 'Here was a death where organs were capable of being harvested; were the family asked, and if not, why not?' - that type of audit on all the hospitals seems in some other States to have lifted their game as far as organ donation is concerned. It does not happen here, I do not think, or we have not heard any evidence that it has.

Dr ALESSANDRINI - I tend to go in myself with the carrot rather than a stick. I think many hospitals would say that it is an additional workload and maybe to provide them with a tool to do this well would be better.

Ms FORREST - It has been suggested that a coordinator could take on that role. We have heard from some witnesses that it wouldn't necessarily just be a matter of conducting an audit on a death that was clearly a potential donor that was missed, but on practically all deaths in ICUs and probably the majority of deaths that occur in the DEMs should possibly be audited because there's always that potential, even for corneas and things such as that. I think some of the suggestions were that if you conduct an audit it makes them much more aware of it. It's not a witch hunt and saying, 'You didn't do the right thing. Why didn't you talk to that family?' It is just doing an audit. If you do an audit of all the deaths that occur in the DEMs and the ICUs, it is not finger pointing as much as looking at how we can do it better. Do you think that's a reasonable suggestion or do you still think that is the stick rather than the carrot?

Dr ALESSANDRINI - I can see where you're going with that. It would certainly raise awareness.

Ms FORREST - More for raising the awareness with the staff, not so much the public and the people who may be potential donors or even recipients.

Dr ALESSANDRINI - I don't know. Maybe an internal kind of an audit, ask them to report on their own procedures. That might be a valuable thing to do. I'm not really in a position to comment on that.

CHAIR - Anything you want to say in conclusion, Megan? It goes without saying that we thank you for your time.

Dr ALESSANDRINI - It's been enjoyable.

CHAIR - Tasmanians seems to do pretty well as far as saying, 'I'm going to donate' when you look at signing the proper form, which you can only get from the Medicare offices, which seems to me to be ridiculous, and not other areas as well. People have filled out those forms to say they wish to become an organ donor and people have also ticked their licences, but when you put the two together, I think 173 000 people in Tasmania said they were willing to donate. But there is nobody who has contacted the people who ticked their licence to say, 'Do you realise you've ticked your licence and kindly agreed to be organ donor?' Because of the way it is now, it should be on a form. This is the form', send the form out and get them to sign it.

Dr ALESSANDRINI - Or walk them through the process even.

CHAIR - Yes. So what has happened is that there are a lot of people out there who seem to think they are organ donors. The population of Tasmania compared with the 173 000 who said they're willing to donate does not come through because of this lack of knowledge of what you have to do. Throughout all the evidence we have had it seems to be a lack of knowledge and education which may well be causing a problem which could lead to a number of recipients, their families and the Tasmanian community as a whole benefiting.

Dr ALESSANDRINI - That would seem like a fairly simple thing to do, to pick up those people if they can be tracked back, to make it easier for them to transfer that consent across.

Ms FORREST - There has been the argument that that is intent when you tick your licence and consent when you do the whole process through the Medicare system. If you still have to get an informed consent from the family at the time, do we really need that? If all those names were recorded so that anyone who registered on their licence with intent and anyone who has consented through the Medicare process were all on a list somewhere, at the end of the day they have registered their intent at least, not their consent. At the end of the day the family still has to give consent to the treating doctors to proceed. We could have an argument there as to whether you need to do that or whether that is enough. I don't know whether you have a view on that?

Dr ALESSANDRINI - I imagine there is a legal aspect to the intent and consent thing. I suppose the other thing is that if people are consenting it is bringing it to the forefront of their minds and they're going to discuss it with their families presumably.

Mrs RATTRAY-WAGNER - Even if they have just indicated to their family and just filled a new form because their previous intent is not current.

CHAIR - Then if it is on a register at the hospital as well - that is not a bad way to approach a family. You could say, 'Look, I know Jim has expressed a wish for his organs to be donated; I want to discuss that issue with you, because obviously he has discussed it with you.' It seems a good trigger to discuss the issue with the grieving family.

Thank you very much for coming along, Megan, and offering us your expertise. We will wait until we see the report from the National Collaborative, which we are told will come down in a couple of weeks. Then we are well on the way to writing a report and making some recommendations, which you will get a copy of. Thank you for your help.

THE WITNESS WITHDREW.

CLINICAL PROFESSOR ANTHONY BELL, DEPUTY DIRECTOR MEDICAL SERVICES, MEDICAL CO-DIRECTOR CLINICAL SERVICES, ROYAL HOBART HOSPITAL, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Wilkinson) – Tony, thanks for coming along. As you know, this is a committee in relation to organ donation and we have been taking evidence now for a few months. We have taken some evidence in Victoria, some in South Australia and also, of course, Tasmania. We are awaiting the National Collaborative report which is due to be handed down probably at the end of this month, although originally we were told it would be the end of December. I understand now that it will be at the end of this month or very soon after. It is probably best before any recommendations are made that we try to dovetail into the National Collaborative report, depending upon what that says. We know you are an expert in relation to the area because of your position with the hospital and that is why we requested that you come along and give us some of your expertise in relation to it.

It is very informal. It is evidence which is taken down in *Hansard* so if you wish to say something that you do not want others to hear, let us know and we can hear that in camera.

Do you want us to start asking you questions or do you want to give a brief background as to what happens at the hospital in relation to organ donation?

Prof. BELL - I thought I would start with a little history of organ donation. In the early 1970s Professor Mitchell at the Royal Hobart Hospital ran an organ donation and transplant unit, which functioned for a few years. But when Professor Mitchell went back to Sydney that stopped happening. In 1979 we started organ donation again at the hospital. We used the brain-death beating-heart organ donation type, which was clearly well in advance of brain-death legislation in Tasmania. The legislation at that time said that the patient was dead when the doctor certified them dead, so we used standard brain-death criteria well in advance of the rest of the country. We did that for a number of years and we had very good success. We basically had a policy in ICU that if anyone became brain dead we asked the family what their wishes were and what their viewpoint would be. Over the years, I think, people slowly became more informed about organ donation and it was not such a controversy to them. Some of the main effects were really the TV programs because people would ask, 'Is the next person coming the donor coordinator?' and we would say, 'That's us' because we have never had an organ coordinator, we have never had those sorts of facilities and it has all been done by the intensive care team. We would always basically follow two people doing everything together so there were no particular issues. Of course the Legislative Council stepped in after a few years of this and decided that brain death was too controversial for Tasmania and removed it from the proposed legislation. I do not know whether you are aware of that?

CHAIR - No. When was that, do you know?

Prof. BELL - I cannot remember the date, it is all a blur, but it was in the mid-1980s. Fortunately after six months of this stand-off, Bob Brown, who was then a member of parliament in Tasmania, proposed brain-death legislation, got on TV and had his

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legislation knocked back, but it was passed a week later with two words changed by the Government. From then on, when multi-organ donors became available, we organised with the teams from Melbourne to come down and do multi-organ donations. I remember a number of those patients and families from that time. We had always run a very active living-related organ donation-kidney donation program and we have a very high percentage of family-related donations in Tasmania. We always have had. We started an unrelated living donor program many years ago but that was really between members of families or people who had exceptionally close ties. We never pushed, and we would not accept, people who were basically random donors off the street who said, 'Give it to Joe Bloggs because I saw him on TV'. We really did avoid that because we felt it was a difficult thing to do.

In the 1990s we learnt how to treat patients with severe brain injury much better and our organ donation rate disappeared because patients did not die of brain death anymore. I discussed this with the nephrologists Australia-wide and the intensive care doctors but none of them believed me, until it happened to them about four years later. Again, this was a feature that Tasmania had started that is called 'intercranial pressure monitoring' where you measure the pressure inside the skull. This was done by Mike Loughhead and Graeme Duffy in the late 1970s and early 1980s. We did it for 10 years before the rest of the country started doing it. We saw these effects well before anybody else.

Since that time we have had a lot of pressure and criticism laid at the intensive care doctors' feet because basically they say your organ donation rate is very low and I keep pointing out that we still have a policy of asking 100 per cent of people. We have the same number of head injuries or traumas coming in but basically most of them survive these days. Brain death is a very rare occurrence.

CHAIR - Are we able to say the percentage of brain deaths in the last five years?

Prof. BELL - I think you have to look at it in two ways and one is we would only use brain death in the case where an organ donation was possible or feasible. Other than that we might do the testing for brain death but talk to the family about withdrawal of support and just let nature take its course. To my way of thinking and my experience tells me it is much more satisfactory for the families to look at someone off machines, not breathing and obviously dead than it is to look at someone who is brain dead, on machines, the chest going up and down, they are still warm to touch, they can still feel a pulse and someone is telling you they are dead, so you only use it if you need to in the case of an organ donation.

CHAIR - Nowadays with organ donation eyes, tissue, a number of areas can be donated. Is it still the same now as opposed to years ago? Am I right in saying, and it is because of my ignorance that I am asking this question, that it was only kidneys, heart, liver, et cetera?

Prof. BELL - No, it is all the same process. The brain death criteria we used in 1979 is the same as we use today. It has not changed and it has never been found to not work. This was really proven by southern American hospitals that had a religious belief that you never stop treating someone. They looked for a number of years at patients who met the criteria for brain death on a single occasion, kept treating them and they found two things. One was if you met the criteria for brain death on a single occasion you always

met it and the second was that you never woke up and you always died. They are the only criteria in medicine I know that have never been shown to fail.

Ms FORREST - There was some information I read that sometimes organ donation is discussed and proposed perhaps before a brain-death diagnosis is made when it is imminent within four hours or a period of time. To me, that sounds a bit controversial, to say to family members, 'Your loved one is going to be brain dead within perhaps four hours but we can do it now if you like, we can take the organs now'.

Prof. BELL - These sorts of cases are very unusual. Some of them have involved brain tumours which are compressing the brain stem and it has been discussed with the person, 'Would you like to be an organ donor? Do you want us to stop treatment?' and then they stop treatment with the expectation that they will die a brain death in the short term and mostly that does not happen. It is just so unpredictable about who is going to become brain dead and who is not in that situation.

Ms FORREST - So it is not really that predictable. That is what you are saying to me?

Prof. BELL - It is not predictable, no. I discussed one of these cases with my colleagues at St Vincents in Melbourne and they tried to go through this process but the patient never became brain dead.

Ms FORREST - Do you think this is perhaps where some of the fears of people stem from? We have heard that some people are reluctant to register as donors because of fears that doctors will not care for them well enough or how do you know they are brain dead and they go in and witness the testing that is done by the medical team but when you hear this is a situation that is unpredictable you need to wait for a definitive diagnosis.

Prof. BELL - Yes, you have to have that definitive diagnosis and you have to call somebody who has not looked after the patient, who does not have a vested interest, to come in and do the whole series of testing again and it is probably unnecessary because all the studies showed if you met the criteria once you always meet it.

Ms FORREST - Is that a challenge in Tasmania, to have those experts available to come in and make that second check, if you like?

Prof. BELL - It was in the early days because there were only three of us and one day the coroner wrote to me and said, 'I'm so impressed by brain death that I want to make every person who dies in Tasmania subjected to brain death'. This was an horrendous thing because there were only three of us who could do it and there is nothing wrong with cardiovascular death, so we had to re-educate the coroner about the role of brain death. But nowadays we have at least eight or 10 people; we have four neurologists at the hospital, four neurosurgeons and five intensive care doctors plus myself. We have enough people to be able to do it.

Ms FORREST - What about if a patient was in Launceston?

Prof. BELL - They certainly have done it from Launceston. When you look at the distribution of neurology and neurosurgery, all those patients with that sort of severity of brain injury come to the Royal. It is very unusual to have those patients -

Ms FORREST - If they don't make it that far they are probably not going to be suitable for a donor anyway, is that what you would suggest? If they end up in the ICU in Burnie, if they weren't going to survive the transfer -

Prof. BELL - When you become brain dead you usually have about 24 hours of stability with quite straightforward treatment. It is a very reasonable thing, if you have talked to the family, to have the patient transported to Hobart, prove they are brain dead and then do an organ donation, especially if you know that is what the patient's wishes were.

Ms FORREST - If the patient is diagnosed or assumed to be brain dead in Burnie, what funding is there to support their medical treatment, care, transport, transfer, readmission and care until that decision is made? Is it adequately funded?

Prof. BELL - Usually what would happen is they wouldn't make the diagnosis of brain death in Burnie. They would have a severely injured patient who is transported. There are issues with what we call 'medical retrieval'. It is a service that has run short of funding. They have had to have locums come in to do it. It was a service set up on a shoestring; I think that is the best way to describe it. It relied on the goodwill of a lot of people to do it.

Ms FORREST - As far as the funding available, once you get the patient to the Royal and establish brain death, what are the funding arrangements to care for that person, assuming they are to be an organ donor? Is it adequate to ensure that you have the staff costs, theatre costs and anaesthetists costs covered?

Prof. BELL - That is all done basically. We expect to do two or three cases a year perhaps.

Ms FORREST - So it is certainly within your budget allocation?

Prof. BELL - Yes. There is no special funding for it. We used to have an arrangement with Victoria. If we put two kidneys into the system they would transplant a Tasmanian off the waiting list because our people were on the waiting list. That was good, except they didn't do anyone for three years. When I rang them up and said they were horrible people they did 10 Tasmanians in a year, which was good.

Ms FORREST - So a phone call helped then, Professor?

Prof. BELL - Yes, it did. People start to look after their own list. These days the aim, because of the shortage of organs, is to get the best match and therefore the best survival rates for that patient and the kidney function. If there are no good matches and you go to people who have very odd tissue types they are never going to get a kidney under that sort of system.

Ms FORREST - We have had evidence that there needs to be a team approach in ICU. Do you think there is any value in having an audit of deaths in ICU and DEMs around the State, not just in the Royal, where potential donors can be picked up?

Prof. BELL - There are two aspects there. One is if you are brain injured from trauma and become brain dead, I think our system picks you up and asks. When I say we ask

everybody, I mean that sometimes it is clear from the family's attitude that they would not consider organ donation. In those cases we don't ask because we don't want to provoke situations. We cover all those people

The group that is very difficult for us is people who have a cardiac arrest that you cannot resuscitate, that you then support because you have a cardiovascular death, and then get an organ donor team in to procure the organs and transplant them. We do not have any surgeons available with the skills to do that organ procurement therefore that group of patients is not accessible to us because you do not have the time available to get a team in from Melbourne.

Ms FORREST - So cardiovascular deaths are really out of the picture anyway.

Prof BELL - They are out of the picture from the point of view of how we could organise it in the hospital. I go back to when we were doing just kidney donations through the 1980s, I had to go up to the theatre to make sure the surgeons knew how to do the operation because they would just want to do an refractomy as they would for a cancer but the operation has technical differences that they were not familiar with and the same would apply today. To do an emergency refractomy of liver, heart or lung is very difficult actually in someone who has just had cardiovascular and you need that team right there and then.

Ms FORREST - The only way of resolving that would be to have specialists with those qualifications and skills here. Is that a reasonable thing to expect or because of our size, do we not do that sort of surgery?

Prof BELL - No, it is because we do not do transplants here and transplantation is one of those areas where the volume you put through a unit is closely related to the outcome. To do 10 or 12 kidney transplants here and two hearts would be a poor move for the quality of care we would provide. We are just too small to have those teams available and be able to do cardiovascular death patients who were resuscitated.

Ms FORREST - That would explain then why Tasmania has a lower conversion rate, for want of a better word, of potential donors to actual donors than Melbourne or Sydney or somewhere else because we miss all those cardiovascular deaths as opposed to brain deaths.

Prof BELL - Yes, that is right.

CHAIR - How many people do we miss out on?

Prof BELL - I would think it is actually a very small number but two or three.

CHAIR - A year?

Prof BELL - If you say two a year that is four kidneys and that is a rate in Tasmania's population eight per hundred thousand and that doubles our rate. The other thing is the transplant people from Melbourne say 'You didn't do any organ donors this year' and I say, 'Yes, well we did six last year'. We have such small figures that the variation can be extreme. I think there was one year where we did none and we did three in January but

they tend to only look at the bad years in which this happens because it is never a good thing.

CHAIR - Sure. Can I run you through a scenario please - and, touch wood, it does not happen - if I walked down the stairs, fell over, knocked my head and finished up being brain dead, I would be taken to hospital, what would you actually do? I would go into intensive care obviously -

Prof BELL - Yes, you would go into the resuscitation emergency department, you would be put on life support systems, transferred to intensive care. Depending on what was happening, whether you were treatable or not depends on what action is taken. If there was a blood clot that we wanted to take out, we would put a pressure monitor in and see if the brain responded. If it became clear that you had no cough - you are given a tube in your throat and most people cough on that - if your pupils became fixed and those types of things became apparent then we would do formal brain death testing. If we had given drugs that would interfere with brain death testing then we would do a blood flow scan of the brain. If you show there is no blood flow to the brain that is accepted that your brain has died. If that is the case then we would basically try to find out whether you are registered as an organ donor or what your viewpoint was.

CHAIR - How would you find that out?

Prof BELL - It used to be good. We would ring up the driving licence people and they would tell us if you had signed.

CHAIR - That is what I was getting at. How do you find out now?

Prof BELL - I have not had to do it for a while but mostly we ring the donor coordinators in Melbourne and they have access to a database.

CHAIR - When you say that, do you just ring them up and they deal with it from Melbourne or do they come over from Melbourne and deal with it here?

Prof BELL - They used to deal with it from Melbourne. We would ask them to deal with specific issues from Melbourne. When it has become much complex with the questions and tissues that you are going to do and a lot of the medical complexities of it which we are not familiar with, we have had the organ donors come over immediately and basically deal with the process. That has been a great help because the complexity and the questions become much more difficult - things like AIDS, hepatitis C, which issues you can use and so forth. You need to be an expert in the area.

CHAIR - You used to ring to find out if they had ticked their licence or not?

Prof. BELL - Yes. Then I went to Victoria to talk to the Victorians and they said, 'We'd better put it on our licences'.

CHAIR - What happened after that?

Prof. BELL - Basically we would ring up and do all the blood tests that were necessary and do all the measurements. I produced a pro forma so you would fill a pro forma out. If everything looked good, we would talk to the family.

CHAIR - Who talks to the family?

Prof. BELL - It was always the intensivist.

CHAIR - Is that still the same?

Prof. BELL - No. A lot of the talking is now done by the organ donor coordinator.

CHAIR - Do we have one here?

Prof. BELL - No, we do not but these are the ones who fly in. The intensivist will talk to them about the brain death and often talk to them in general terms about organ donation and introduce the donor coordinator. We try to keep the two processes separate. There is a doctor looking after the patient and once the patient is brain dead he introduces them to discuss organ donation. I think that is a good thing. In the old days sometimes I was there by myself and you would have to do both. In those situations we found that if the family trusted you and saw that you were doing the best for the patient then it was not an issue but obviously it is a more difficult thing to do and it has legal ramifications; you did not treat them properly because you wanted their kidneys.

CHAIR - Therefore the coordinators come from Melbourne to speak with the family. If they can see that the individual has consented to their organs being donated but the family say they do not want that to happen, what happens then?

Prof. BELL - That happened a long time ago to me and it was very interesting. I asked a family what would their daughter want and they said, 'We're totally opposed to organ donation'. I said, 'That was not the question. I asked what would your daughter wish'. They said she wanted to be an organ donor.

CHAIR - So did the donation take place?

Prof. BELL - The donation took place then and the family rang me on the ninth anniversary of her death to see what had happened. I think it is important that we did what the patient wanted, and that is our responsibility.

Ms FORREST - Is there a fear of litigation in that, if they said they did not give their consent, even if she might have indicated that she wanted to do that?

Prof. BELL - No, they gave their consent because I had asked the right question. They said, 'We're totally opposed to organ donation but that is not saying we won't give consent'. I just asked them what their daughter would want and they knew she wanted to be an organ donor so they consented to that. The question of course is do you need their consent to do it. Our legal advice at the time was that if you had signed your licence then you could do it without consent of the family because that was the patient's wish.

Ms FORREST - Having signed their licence was considered an informed consent, was it?

Prof. BELL - That was the opinion we got from the Solicitor-General, yes.

Ms FORREST - How long ago was that?

Prof. BELL - It was a long time ago - 15 years ago. These issues have been around for a long time.

Ms FORREST - Yes, I know.

Prof. BELL - But we would never do that because the one thing that you do not want is people who have been organ donors and their family and then are opposed to it. They say to you, 'You don't know what it's like. You have never donated'. And you cannot argue with them. So you have to have the family's agreement and if they had refused, we never would have done an organ donation because you just can't afford to have that type of opposition to it. It is very damaging and extraordinarily difficult to deal with.

CHAIR - Do you find that the more experienced the asker, for want of another word, is the better it is as far as informing the family of what is to occur and whether it should or should not happen?

Prof. BELL - Yes, and that is why we always have the consultants doing it. Occasionally we would have a senior registrar who is going to be a consultant the next year do it but you would sit in with them and make sure all went smoothly, keep an eye on it and try to have them so they could understand what was happening. You need that touch of empathy with the family. The doctors who do not have it, we would prefer not to have ask.

Ms FORREST - Professor, do you believe that having some sort of training with doctors as they go through their training would be helpful in that situation or do you think it is something that you just learn when you need it?

Prof. BELL - I think the doctors who are going to be involved need to learn and ask. There are the Australian Donor Awareness programs and other things to train them and they should do that. They should learn how to do it, but it is very few doctors so it is not something to put into a medical course; it is not something 99 per cent of doctors need to concern themselves with.

Ms FORREST - Have all your staff done the ADAP?

Prof. BELL - I think half of them have.

Ms FORREST - Would you prefer them to do it and would you encourage them to do it?

Prof. BELL - All the trainees in intensive care medicine now do it as part of their joint fellowship.

Ms FORREST - Talk about the nursing staff, particularly the senior nursing staff.

Prof. BELL - We have had a number of nurses do it and we have a number who would be quite suitable to be organ donor coordinators but there is no funding.

Ms FORREST - Often the relatives will go back to the nurse and say, 'What would you do?'

Prof. BELL - Yes, and mostly if we have a brain-dead person we have a senior nurse either looking after the patient or in the cubicle next to them with a junior nurse to provide that sort of support that you need.

Mrs RATTRAY-WAGNER - Following on from Ruth's question about the organ donation coordinator, do you believe that Tasmania should or would benefit from having their own organ donation coordinator within the State?

Prof. BELL - It would certainly make things a lot easier, I think. If we could raise awareness in the hospital it would allow that person to deal with a lot of other peripheral issues. For the first time, for example, as a peripheral issue we had a multi-organ donor. The teams all arrived at three o'clock in the morning so I went up into the operating theatre and there was a nurse crying. I said, 'It's fine. This is good. We're going to save other people's lives from someone who's already dead'. She said, 'You don't understand. This is my best friend's son'. That is something you just do not see on the mainland. You have to then debrief, counsel and look after these people because it is very traumatic. It is all those sorts of peripheral things that are very hard. It is not really a good role for an intensive care doctor to be playing, going around and debriefing and looking after the staff but it would be a good role for an organ donor coordinator who has the facts at their fingertips and can say, 'This donation did this and this and this' - things like that. It is also the issue we have had because of the difference in the legislation. We have had the case of the Victorian organ donor where, halfway through the operation, they said, 'Stop, stop, the patient's not dead', which is fairly disturbing. It is really a difference in the level of barbiturates available by law in Tasmania and Victoria. Victoria has a zero and then we have no legislation. If your barbiturate is that of a tenth of the level of someone walking around the street being treated for epilepsy we do not believe that affects brain-death testing.

CHAIR - Should our legislation be changed in any way?

Prof. BELL - No.

Ms FORREST - Following on from that, there have been articles written and if you go onto the Internet particularly, which is always a dangerous thing to do because you get all sorts of unrefereed articles, people think if a patient needs anaesthetic, or muscle relaxant is probably more what is used, I imagine, then are they really dead? You get muscle spasms; it can make it hard to get organs out of the abdominal cavity and the like. Can you explain a bit about what sort of drugs are used and why in the operating theatre.

Prof. BELL - They are mostly given as a standard anaesthesia with pain relief and muscle paralysis. The muscle paralysis is essential because of the peripheral reflexes, so it is pain, spinal cord and muscle reflex. It is like any abdominal operation; you need to paralyse the muscles so that you lift the abdominal cavity open and access the organs. Pain relief is given because if you do detailed studies into someone who meets brain death criteria, there are probably areas of the brain that are still alive. Brain death really

refers to death of the brain stem. If your brain stem does, we know that the rest of the brain follows in a period of time afterwards - usually about four to five days. Therefore, the question is whether the trauma to the rest of the body affects the brain function? Can the person feel? We have no way of knowing that answer; therefore it is safer, better and generally more humane to give an anaesthetic agent and pain relief agent. Also there are other reflexes that release auto catecholamines and other things from peripheral reflexes and you can damp down the effect of those drugs on the heart rate and other circulation by using an anaesthetic. But they are all given post diagnosis and confirmation of brain death. Of more concern are the drugs given in ICU to sedate someone and making sure that they are not influencing the diagnosis of brain death.

Ms FORREST - That is when you do the blood flow of the brain studies?

Prof. BELL - If there are any concerns about it we would do a blood flow study of the brain and basically we use a carotid angiogram. You have to do the carotid arteries plus the vertebral arteries. The dye goes up and stops at the entrance to the skull and that indicates that the pressure inside the skull is greater than the blood pressure. Often when we are measuring the intracranial pressure, we know that it has been higher and usually you lose the trace when this occurs - just for technical reasons.

Ms FORREST - Do you get many people who, when you have counselled them about their loved one going through this process, have concerns about that? Anecdotally, in the information you can read, it would suggest that that is the case, but in practice does it seem to be the case?

Prof. BELL - No, it doesn't really. In our relatively small unit we have looked after the patient and done the testing and we have a very open disclosure discussion policy with families visiting and so forth. I think that mostly the families have learned to trust us and they see that we are doing the best for the patient. It is very unusual for someone to come in and to be brain dead very quickly. If you explain to the families and show them the scans, we find that most people trust us to do the right thing.

Ms FORREST - If people seem to be reluctant to register as donors or to consent to their loved ones having their organs donated, what sort of educational program is needed to assist with that and how would it be best delivered?

Prof. BELL - I don't know how you do that.

Ms FORREST - You just focus on educating your staff and leave the public to someone else?

Prof. BELL - I don't know how - I am not an educator. I know that the Kidney Foundation has had a program they got in from America. They had a program for the schools and they have covered a few schools in Tasmania. I don't know anything about changing public perception.

CHAIR - Let me try to summarise what you have been saying - and tell me if I am right or only halfway there. The advances in medicine have meant that fewer people are now available to donate their organs, since it first occurred in the 70s, when Tasmania seemed to be piloting organ donation to some degree. The ICU at the Royal and within

Tasmania has in place a policy in relation to organ donation and you are satisfied that that policy is being met.

Prof. BELL - Yes, it is interesting to remember one time when it wasn't met. The nurses just rang me up at home and said, 'So and so is not doing it; you have to come and do it.'

CHAIR - Some evidence we have had from other States says that what is of assistance in relation to making sure that it is met is to have an audit.

Prof. BELL - Yes, I know the audit tool -

CHAIR - Does that work?

Prof. BELL - I have no idea really, but in our system, it was identifying people who were dying on the wards with cardiovascular death and doing organ donations - we just do not have the ability to do the audit when as a State, we appear to have, at the best, three to five organ donors a year.

There is a huge amount of work and it is something that basically I made a decision not to do a number of years ago.

CHAIR - And is that what is occurring - there are within Tasmania over the past five years approximately three to five people who donate their organs?

Prof. BELL - I think so. I used to keep the figures, but I have too many roles now.

CHAIR - An organ donor coordinator would be of assistance, but presently there is no funding for it.

Prof. BELL - It would be of assistance. You would really look at having three or four of the renal ICU nurses trained to do it, so you kept one available, one on call.

CHAIR - With all these matters there would be funding to take into account and if you employed a specific person to do the role, is the money better spent doing other things, considering the statistics you have just given us.

Prof. BELL - People have pushed us for many years to say that we need an organ donor coordinator. The complexity of it has become such that it is now a role that we do need. If you had asked me five years ago, I would have said it was hard to see the need. But it is a different business now - it is just so complex; you have to keep up with it, you have to educate people. In the old days I said do you want us to get the HIV testing done?' and Melbourne said, 'HIV testing? I would never have thought of that.' I thought, 'Oh no, who are we actually dealing with here?' But nowadays they change the protocols every month or so - and usually forget to send us their changes, so that when we do things we usually run into hiccups and barriers. We need the organ donor coordinator. I would not have a person - I think it is a role for three or four people, even if it is in a part-time role with their other positions to basically keep on top of all those things.

Ms FORREST - Do you think they should be spread around the State so that you could have educational programs as well?

Prof. BELL - I think they should do education programs in the north of the State, but I think they need to be centred at the Royal because that is where most of the patients end up.

CHAIR - In relation to people giving their consent, we have heard that approximately 173 000 people in Tasmania have either ticked the licence or registered with the form from Medicare offices. Is there a better way and should Tasmania be able to readily access that data?

Prof. BELL - When driver's licences were started here, the change was that people talked about it with their families. It wasn't that we could access information, but that discussion took place. I remember with one patient we were asking the family and the husband said, 'Look, I have no idea what my wife would want', but the 14-year-old daughter said, 'Mum and I talked about that with the licence, and she would hate to be an organ donor.' That is where the discussion was the important aspect of it rather than what box you ticked or didn't tick. I think that is the great advantage of these programs, rather than what people actually put down. I don't know how you go about pushing it more and whether it is the right vehicle. That is a bit out of my league. It is having something there that people can do, talk to their family about it, and the family know what their wishes are. That is the important aspect.

CHAIR - Sure, I understand that. Does it make it easier for you if you know the wishes of the individual?

Prof. BELL - It is nice if you do know because you can be a little more forceful in your questioning. You can say 'This is what your family member would wish, why are you saying no?' You can push a little harder. But that is an unusual situation.

CHAIR - We have been told 'educate, educate, educate' and if, by educating, you allow the family to talk about it more readily, it makes the job much easier. You hope it never has to happen, but if it does happen -

Prof. BELL - At least people know the opinion and then the family don't feel guilty about saying, 'Yes, do it.' I think that is another important aspect.

CHAIR - In relation to the report that we hand down with recommendations, do you believe that it is essential, or certainly worthwhile, that we wait for the national collaborative report to come down in a few weeks time because it would be better to dovetail in with that, as opposed to striking out alone?

Prof. BELL - I think so. As long as they don't have extreme views in it!

Laughter.

Prof. BELL - There are some issues that come up from time to time. Twenty years ago we tried through Bob Brown to put in an opt-out system, but that was rejected by the Parliament. But what do you do with the altruistic donor, which I think is a very vexed issue. One of the things that I think is wrong is for someone to say, 'I want to give a kidney to you' and then go out and push that. There are all sorts of motives and things behind that and it seems to me that the New South Wales legislation is practical and

sensible - that the donor can be a donor if they wish to give a kidney, but it goes into the same processes as a brain-dead donor and cadaveric donor - to the best-matched person. Contact between the two is limited in the way it is now between families and recipients.

CHAIR - Does Tasmania take that into account with its legislation?

Prof. BELL - Altruistic donors is not a matter that has come up.

CHAIR - Are you saying Tasmania should look at it?

Prof. BELL - I think we should look at it. The estimation is that we would probably have three to five donations a year through that sort of process.

CHAIR - And the problems that are now within the legislation are that it does not look at that issue, or does not allow it to occur?

Prof. BELL - I think it is putting in place the legislative framework so that it happens in this anonymous, altruistic way. What we are trying to avoid is the sort of situation where someone says, 'I'll give my kidney to your son, but you have to be my best friend now.' These external motives have to be eliminated.

CHAIR - So if we follow the New South Wales legislation, do you believe that would be helpful?

Prof. BELL - I think that would be a good move.

CHAIR - Any other things you believe should be in the recommendations that we make?

Prof. BELL - I often thought opting out would be good, but I have lost the momentum on that and I don't think it is a good way to go now.

CHAIR - I must admit I had that thought at the outset, but the evidence we had from Texas, where that was the case, was that 80 per cent said no because they did not want to be told what to do.

Prof. BELL - It looked good when Bob Brown brought in the legislation for brain death, but it didn't go anywhere. It was 10 years ahead of the South Australian legislation and no-one had really considered it. It was just one of those ill-conceived ideas that I picked up from the Spanish!

CHAIR - But it creates debate and debate creates education. It gets people talking, doesn't it?

Prof. BELL - Yes, but the wrong way!

CHAIR - Anything else you think we have missed?

Ms FORREST - The issue with the coroner - you had to educate the coroner some time back - I assume most tragic deaths are coroner's cases. Can you explain how the coroner fits into that?

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Prof. BELL - These days once you have someone who is brain dead and you wish them to be an organ donor, you have to get permission of the coroner to do the donation procedures. The coroner then satisfies himself that if, say, it is a violent crime, he is not going to lose evidence as to what occurred at the time of the incident. He needs to know that the family is agreeable and have signed, and he needs to know that the designated officer has signed. If you meet all of those criteria, one of the surgical team has to write a report on the health and wellbeing of the organs and the rest of the body, and that basically becomes part of the coronial autopsy.

Ms FORREST - That is done during the retrieval process?

Prof. BELL - Yes, the retrieval people would do that.

Ms FORREST - Any drug testing or things like that of registered licit or other drugs or compounds, poisons, whatever, would be done in ICU?

Prof. BELL - Usually we would look at that, and if it is a violent crime then the police come and collect evidence, take photographs, take whatever blood samples they wish - that is pretty standard. We used to have problems, but once the coroner has understood brain death, the biggest issue we have is often the time of someone's death.

Ms FORREST - Getting the coroner out of bed?

Prof. BELL - No, we put down the time of death as when the first brain test shows that you are dead because that is the legal definition of 'death'. The coroner sometimes has said it is when the heart stops beating, but sometimes the heart is still beating a year later. It has been a touchy thing because people insist on a time of death.

Ms FORREST - Obviously you hope the heart does keep beating in someone else's chest. Does there need to be a change in the Coroners Act?

Prof. BELL - It would be nice if the time of the first brain death testing of proved brain death were formally made the time of death.

Ms FORREST - Is that an area that needs to be looked at within our legislation - the definition of 'death'.

Prof. BELL - It is not the definition, it is the time. Some people say it is the first testing for brain death, but, as I said, once you are brain dead once you are always brain dead. Some people like time of death to be the second brain testing and others prefer when the heart stops beating, which it does for a period of time when you take it out. If there were no organ donation, we would rather take off the life support and let the person die naturally. In that case we just use the permanent cessation of the circulation as the time of death. It would be nice to have that defined because we have had people who wanted death certificates reissued because they thought the person died at 11.55 p.m., but they died at 12.10 a.m. It just creates issues.

Ms FORREST - When people want to remember a day, it is important that the day is the correct one.

Prof. BELL - We would like that clarity.

CHAIR - And the confusion is because of the legislation or the practice that has arisen?

Prof. BELL - Because brain death testing is done twice and you have an operation where the heart stops, people use different times - first testing, second testing, when the heart comes out of the chest - as the time of death. It really is the time of the first brain death test.

CHAIR - Is that in the Coroners Act?

Prof. BELL - No, I think that would be in the human tissue act. We want just one line.

Ms FORREST - A simple amendment.

Prof. BELL - I think so - something along the lines of 'the time of death in organ donation will be the time of proving brain death.'

CHAIR - Tony, thank you very much for giving up your time and busy schedule to come here and give us the benefit of your expertise. It is very helpful. We will wait for the national report to come down; we will have a look at that. We have taken pretty well all the evidence we need to take, but something might crop up between now and when we

get that report. I think we will be able to report within a month of receiving the national report. You will receive a copy and hopefully it will assist.

THE WITNESS WITHDREW.