

**THE LEGISLATIVE COUNCIL SELECT COMMITTEE ON ORGAN DONATION  
MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART ON TUESDAY  
2 OCTOBER 2007.**

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**LARAIN PATRICIA DONNELLY** WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** (Mr Wilkinson) - Laraine, thanks very much for coming along. It is an informal procedure so please do not feel nervous. It is a procedure where we normally give you the opportunity to give us an overview and then, after your overview, we will ask questions.

As Paul just mentioned to me, Laraine, this hearing is being recorded on *Hansard*, so everything you say will be noted down so, if you do not want something recorded, please let us know and then we can discuss whether it should be in-camera or not.

**Ms DONNELLY** - Okay. First of all, I would like to say thank you very much for the opportunity to speak to you all. I am speaking as a private citizen on behalf of the people who signed the original submission and people whom I know. When I read the terms of reference of this committee, it occurred to me that I would like to address those terms of reference to examine the paradigm they have come from. So I will just go ahead if that is okay.

**CHAIR** - Sure.

**Ms DONNELLY** - Supporters of organ donation appear to view the practice as a productive, positive and safe action for the individual to take and that people must have the option of receiving a new organ if they need and want one. This ideal would seem to be based on the benefit of new life that the recipient can receive after transplant surgery. This new lease of life may vary from one to five years or even continue for their natural lifespan. Research into the techniques and benefits of transplants for recipients have been accelerating for a number of years. However, there has been, to my knowledge, no official research into the effects of the organ harvesting process on the donor, especially now that the definition of death has come to mean brain death.

Research and scientific investigation have begun in this area, but many questions need to be satisfactorily answered before informed and fair legislation can be embarked upon - and that is just my opinion on the matter.

Questions arise such as: is brain death, the diagnosis of death that is now used to determine if organ harvesting can begin, accurate? That is on the first page here. There is an article called 'What is brain death? A British physician's view.' In this article, he states:

'In the present state of knowledge there is no sound scientific basis for the diagnosis of human death on the so-called "brain death" or "brain stem death" clinical criteria in current use worldwide.'

There are a lot of differing opinions from that aspect of death.

Can testing a possible donor for brain death actually cause death? Associate Professor Cicero Galli Coimbra, the Head of the Neurology and Neurosurgery Department at the Federal University of Sao Paulo, Brazil, and Dr Yoshio Watanabe, an academic and cardiologist at the Cardiovascular Institute, Fujita Health University School of Medicine in Toyoake, Japan, both seem to think so. There is evidence to suggest that some of those things might be happening.

Does brain death actually mean that patient cannot be revived? There is a whole web site devoted to people who have recovered, in some cases, after having been classified as being dead. The most recent example is a lady called Pam Reynolds. She went through a new type of surgical procedure where, literally, she was put to death. All the monitors that were attached to her body actually showed no life signs whatsoever. Then they did the operation, and during this time - if you read her personal account - she can detail everything that the doctors were doing. It is quite interesting. In fact she came back from being what is called 'brain dead'. These are the kinds of issues that are coming up.

If patients can recover after being brain dead, does this mean that some donors, who would otherwise recover, are being killed while their organs are harvested? If you turn over the page, there is an article called 'Healing Treatments Denied to Potential Donors'. Does the urgency of having to prepare the donor's body for harvesting preclude the use of treatments or time spans that may in fact allow recovery? So some doctors are saying that if these people were not organ donors, they would perhaps be treated differently and left longer. So they are looking at that aspect of it.

Another question is: does the organ harvesting process cause pain for the donor? If you go to the next the page, you will see 'Donors may need Anaesthetic'. It says that Dr Phillip Keep of the UK publicly stated:

'Almost everyone will say that they have felt uneasy about it.'

He is referring to taking out organs -

'Nurses get really, really upset. You stick the knife in and the pulse and blood pressure shoot up. If you don't give anything at all the patient will start moving and wriggling around and it's impossible to do the operation.'

Another question is what are the effects of organ harvesting on the state of the person in the next life. Some religious thought believes that a person goes to the next world in the condition that they die in, which is not a very pleasant idea if you are an organ donor. This article here talks specifically about that situation.

Recent studies on what doctors call 'cellular memory', for instance - the recipient taking on some of the personality of the donor - could be interpreted from another view point. For example, the donor may have become attached to the recipient - 'Ghost Whisperer' style - and cannot continue their journey in the next life. That is a real concern for people who have that religious belief. This article here, 'Knowing By Heart' - and there are some more other articles from another magazine - are all about cellular memory.

At the moment reliable research information about what happens to the donor in organ harvesting is in its infancy. Many fear that we have considered organ donation as a positive thing on a very limited and biased body of evidence - that which concerns its effect on the recipient without due consideration or understanding as to what happens to the donor's life or death.

Science is just advancing into areas where they can start to measure things such as unseen energies. Considering the second part of the current paradigm, the optimum situation being considered is that everyone could have a transplant if they or their doctor felt they needed one. A different viewpoint would ask what would be the negative consequences of such a thing. Maybe it might be similar to what has happened with abortions. There are now between 80 000 and 100 000 abortions happening a year in Australia. When those kinds of operations have become so easily available, other things happen in relation to people's attitudes about them. Would public health be affected? Would we see a greater increase in self-inflicted organ disease from over-indulgence in food, alcohol, tobacco and drugs? Further on there are some details from a doctor about the conditions that are actually causing organ disease. Do we want to encourage a continuous rise in the need for organ transplants by taking this way without considering a lot of other options? I think there are many questions that need to be considered before you can have really fair and equitable legislation on this matter.

**CHAIR** - There is legislation already in relation to it, as you probably know.

**Ms DONNELLY** - Yes, I know. I'd just like to go onto the terms of reference and tell you my experiences and comments from people whom I know about these terms of reference. They certainly do not cover them in a very deep way. Firstly, I would like to look at item 1, which concerns the adequacy of the present system. I would like to present as evidence two incidents drawn from a small group of people I have spoken to in Hobart. Both of these incidents involved errors occurring when the person was trying to ensure that they were not on the organ donor register. This first letter is from Gary Smith and I think that was in the first submission. Gary's wife went to the Glenorchy Medicare office to submit forms stipulating that they did not want to participate in organ donation, but when she got home a short time later she received a phone call from one of the staff at the Medicare office stating that they had not indicated which organs they wanted to donate. So it was obviously the mistake that happened straight away. The second incident occurred a bit earlier and that is over the page and it is a lady called Lorraine. In 1999 she decided to have her name removed as an organ donor from her driver's licence. She went through the proper procedure but when she received her licence back the organ donor name was still on it. So if she had died in the time between when she no longer to donate and the time that eventually it was taken off she would actually have had donated organs against her own wishes. So we are just pointing out that there are already errors happening in the system and any future system would need to really look at how efficient it is so that errors that would cause emotional, social and legal distress do not occur.

**Ms FORREST** - Are you aware of any of those errors happening with the registration system through the Medicare consent process?

**Ms DONNELLY** - I am not and this information is from a very small group of people.

**Ms FORREST** - They are still related to the driver's licence system.

**Ms DONNELLY** - One was related driver's licence system and one was related to the new Medicare system.

**Ms FORREST** - It was to the new Medicare system?

**Ms DONNELLY** - In 2007 - it happened this year. Item 2 deals with the adequacy of Tasmania's present approach to identifying potential donors. It is my understanding that at present we have an opt-in system, which, although it may have issues of low participation rates, adequately determines those at least at some time wanted to be on the register. It does not leave itself open to the problems of an opt-out system where, because of a lack of action on the part of an individual or an error in part of the system, organ harvesting may take place without true consent.

That is of concern for quite a few people. The opt-in system generally avoids the possibility of causing undue suffering to a greater degree than the opt-out system, lessening the chances the litigation or social disturbances that might occur, especially if an unwilling donor of a faith that is opposed to organ donation is actually accidentally harvested.

This first letter is talking about energy fields around the body and how some of those can be affected by organ donation. The next one is just about the difference between opt-out or opt-in and some of the problems that may occur. A little bit further down here - and this off the Internet - it says that Brazil chose an opt-out situation. One of the comments from somebody was, 'Now we are doubly afraid of being hit by a car. We were always afraid of crazy drivers, now we have to worry about the ambulance workers who may be paid on the side to declare us dead before our time is really up.' Such a system can really open up to malpractice, I think.

**Ms FORREST** - In Australia ambulance officers cannot pronounce someone dead. It must be different in Brazil.

**Ms DONNELLY** - It probably is.

**Mr FORREST** - Yes, they cannot do it in Australia.

**Ms DONNELLY** - On the next page, this comes from Patmalar Ambikapathy, she was the Commissioner for Children here a few years ago and her husband who is a Consultant Physician. They made some comments on two different perspectives.

First of all, it has brought together the differing views of faiths about death and brain death - all the different issues. As it says, there are some churches have not caught up with the difference between heart/brain death and just brain death or brain stem death. So they do not have an official policy on it at the moment but as this goes along I am sure that will probably happen.

In the memorandum, Dr Arunasalam Ambikapathy, who is a consultant physician, is looking at item 3, which looks at the impediment to organ donation rates. Just from a personal opinion, quite a few of the people I talk to do not want to donate. They feel

uncomfortable about it - especially as they are not really sure what happens on the table or after death. They do feel uncomfortable about it.

The next part of it looks at the net worth to Tasmania of having an increased level of participation in donating organs and harvesting them. In the first part of the medical perspectives from the consultant physician - and he is very well respected physician in Melbourne who works at the university - his views are that organ transplants are not cost effective compared to the provision of therapeutic and preventive medical services to patients. Immunosuppressant drug therapy necessary after all transplants can cause significant morbidity and diminish the patient's quality of life over their lifetime. Organ transplant patients are prone to developing cancers as a consequence of long-term immuno-suppression. Many patients, relatives and the public are ill-informed about the cost of transplants, its unwanted effects, risks and benefits. His opinion is that for Tasmania in particular the health system would benefit very much more if funding for a transplant unit was spent on badly needed primary care services around the State. He says:

'The provision of therapeutic and preventative initiatives for major disease are in limited supply in Tasmania and the health dollar would be better served in these areas, understanding that Tasmanian patients who need transplants could well be served at interstate centres.'

So they are just some of his opinions.

If you turn over the page it has a bit of an odd heading but I have marked prevention. It looks at our unhealthy lifestyles. This is from 1997, which is quite old, but researchers suggest that 100 000 first time heart attacks could be averted by the year 2005 - and this is American information - if Americans simply reduced their average saturated fat intake. So it is trying to make a really bigger effort in helping the general public understand why they may get ill and how they can prevent such conditions that may require organ transplants in the long run.

The question of how much patients change their lifestyle so as not to require further transplants? I know in the first submission Gary recited the story of his friend who had a liver transplant and continued his alcoholism and then died of liver failure afterwards.

Another aspect that I think needs to be considered is the number of lives that would be lost due to the early diagnosis of brain death and thus organ harvesting in a patient who would have recovered given sufficient time and related medical care. I think an ongoing concern for people around the world is that once organ donation becomes a very big medical business, I suspect that the time and effort, the therapies that may be offered, may not be offered. I think previously there was an article referring to the fact that in some cases some doctors pursued exactly the same thing - that there are more steps that could be taken may not be taken, so those lives will be lost because of that.

The kind of ethical question remains: if it is possible for a person to return after being brain dead but organs are harvested in an urgent manner, is that murder or what is it? They are the questions that people are asking.

The long-term effect of the message being sent to the general public through a bigger promotion of organ donations is best in an opt-out system. That the responsibility of one's own organ health can be abandoned as one can always use those of another.

My profession is an educator and over the years I have looked at the areas where promotion of something has an unwanted consequence and I would like to share with you one experience that I had. I was talking to a gentleman from the fire department about how learning takes place for children. I said that it was not what you say to them but what they observe is what they learn. He said, 'We have been having a little problem with our program with children who may have lit fires. We take them to the fire station and show them the fire engines and talk about fires, give them a badge, make them want to be firemen, but our problem is that their siblings or their friends then go and light fires.' So they were having a program to try to reduce the incidence of children lighting fires but, because of their style of delivery, it was seen by other children who were observing it as being 'if you light a fire you get special treatment.'

When you promote something you cannot be sure of the consequences of the people of observing what happens with that promotion. If we promote opt-out legislation and organ donation as the best way to treat organ health, what does that do for people who observe that promotion? How does that make them think about what they need to do about their own health? That is an issue. It doesn't mean that they may think, 'I don't really have to be so concerned about how I care for my body because there are plenty of organs available. If push comes to shove, I can have someone else's'. So those are the kinds of things that we would like to consider and what message is being sent to the general public, whatever legislation is enacted.

The other thing is the consequence of a swing away from research in the areas of preventive medicines and alternative solutions. In other words, if we promote organ donation to this degree, it is very likely that research into other methods will tail off. Then you get stuck in a situation where, instead of having ways of where research can overcome the issue and help promote organ health without having a transplant, you get locked into a kind of system. They are the questions that people are concerned about.

I think the trade in organ donation that is being fuelled across the world, we know from one way is because there are not enough organs, but in another way there are not enough alternatives either. That goes on about the level of research, and then we are back to the memorandum - this is the second part.

Another is the consequence of the message that an opt-out system would send concerning State ownership of an individual's body at a certain stage in their life or death. For many this could appear to be a rather insidious attack on the democratic freedom of the individual Tasmanians. From the human rights perspective, Patmalar Ambikapathy has listed that each person has rights over their own body to the exclusion of others and that no individual or state has the right over any person's body. In an emergency situation the law allows for intervention to benefit the person who is suffering. In the case of children, there is established law that limits parental input. Looking at those laws concerning children, whose parents may want to donate their organs, there is no inherent right for the state to intervene in the health of the person to the exclusion of the wishes of that person or that person's next of kin. These are all legal questions that she has brought up.

There is already provision in Tasmania for voluntary decision-making about donations and organs to benefit the third person. The right to choose and the freedom to give informed consent - and I would like to look at 'informed consent' in a little while - are fundamental rights in a democratic society. One of the problems with an opt-out system is the right to choose for people who may have their mental or emotional health impaired. There are many questions about those kinds of systems. Legislation for compulsory organ donation is, in her opinion, 'an unwarranted erosion of an individual's rights, when the option to inform and educate has not been actioned.' So thorough education programs and information are needed.

Religious or ethical beliefs are relevant and must be respected in a plural society. Neither the state nor a third person has the right to the organ of another person. This is her legal perspective. The consequence of an error in a system which is an opt-out system is greatly increased. The high risk of harvesting without true consent is increased. One concern is that in today's climate, where, if there is an error, an individual or family members who feel wronged by the system have a capacity to take revenge in a violent and very extensive manner, as has been viewed across the world. This is far greater than it used to be, so those errors may cost many more lives than erring on the side of caution.

**CHAIR** - We had a lot of evidence yesterday to show that the opt-out, as opposed to the opt-in process, doesn't work. I don't know what other members think, but I know that a couple of witnesses stated the opt-out process doesn't work. They stressed that it has to be 'informed consent', and there should be an education process in relation to this to see whether people do or don't want to. But it's not a matter of don't want to, it is whether they do, because you don't have to opt out.

**Ms DONNELLY** - Yes. An opt-in system is much safer from all those points of view.

**CHAIR** - That was the strength of the evidence yesterday from the medical fraternity as well.

**Ms DONNELLY** - Yes. It is certainly the feeling of a lot of people that it is much safer. I had one young girl - admittedly she is an alternative medicine person - who said that if there was an opt-out system she wouldn't want to go to the hospital. She would be ethically opposed and anxious about even going to the hospital.

Item 5 looks at education and promotion programs, which you have been talking about. Our feeling is that a balanced view that takes religious beliefs into the consideration, provides an honest explanation of what happens when they happen on the operating table, and also provides the latest evidence available from recipients as to their after-transplant experiences, is essential. I think a program is necessary that takes a middle position on organ donation - one that shows both areas, not one that is absolutely anti or for, just something that is really straight down the middle.

This last bit I have put in the back of the submission is actually from America. There was research done in 2006, and one of the concerns that they have is that as it goes along, organ procurement organisations, Internet and enrolment organisations, are actually abandoning informed consent. One of its conclusions is that the web sites and

consent forms for public enrolment in organ donation do not fulfil the necessary requirements for informed consent.

The web sites predominantly provide positive reinforcement and promotional information, rather than the transplant disclosure of the organ donation process. Individual regulatory oversight is essential to ensure that Internet enrolment for organ donation complies with legal and ethical standards for informed consent. So that is another concern that they have brought up in terms of education and promotion programs - that they are really informed.

I did have a look at one of the sites for enrolment for Australia, and I would have to say you couldn't consider it to be informed. There was a little bit of detail about some of the procedure, but there certainly wasn't any kind of 'this may happen, or that may happen'. People may think this happens or that happens, but it certainly was not wide enough to be considered to be 'informed'.

**Ms FORREST** - Do you think that forms such as those that go out now through Medicare - similar to that, but not necessarily that particular form - with written information that is middle of the road, as you described, by looking at both sides of the argument, would constitute informed consent, without someone actually sitting down with someone who can provide answers to any questions they might have?

**Ms DONNELLY** - What do we do for things like IVF programs or abortion? I think we have to have some counselling for people. I don't think the forms would be sufficient, but that's my personal opinion. If we do it for such things as IVF - gaining life - surely we should do it for giving organs away, and perhaps even taking your own life. I would have thought that an informed consent would have to be fairly thorough.

**Ms FORREST** - Do you think there is a way that informed consent can be achieved in a written form? Could people just go to the Medicare web site, click on a button to find out about organ donation and read the information, but then be directed to talk to a person, depending on which State you are in, and they then provide further information and answer questions? Would that be necessary to get informed consent? How do think it could work?

**Ms DONNELLY** - I think it would be because you cannot tell the condition of a person who is actually reading the information. You do not know what is happening in their head. I have another example of a man who was severely depressed and he thought that the only thing he could do of any use was to donate his organs. That is not informed consent - let us be real - because he is coming from a position of mental illness.

**Ms FORREST** - Who do you think should obtain this consent then?

**Ms DONNELLY** - I do not have a problem with Medicare, but you would have to have a person in that situation who could then say, 'You have filled in the forms, please come and talk to me about it'. Then they should ask the question, 'Why do you want to do this?' I do not know any other way you could really know that people were in appropriate condition to do it, especially when we cannot guarantee what is going to happen to them.

**CHAIR** - Laraine, time is starting to march on, unfortunately. We do the best we can to keep to the timetable. If there are any other final questions that need to be asked, please ask them. Otherwise, thank you very much for coming along and thanks for giving us your submission.

**THE WITNESS WITHDREW.**

**Ms NIKKI NOLAN WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.**

**CHAIR** (Mr Wilkinson) - Nikki, thanks for coming along. It is an informal process and we want you to feel as comfortable as possible in putting forward your submission, which you have already supplied to us.

**Ms NOLAN** - I did not have time to actually sit down and put it on paper but I do feel that sometimes it is much better to talk face to face because I am a donor mum.

**CHAIR** - I understand that, thank you. I just indicate to you that this is being recorded and anything you do not want recorded for whatever reason please let us know and we can discuss whether that should or should not be in camera, in other words, in private. We have listed here 9.30 a.m. to 10 o'clock for your evidence and we are already running a bit late. Please do not feel too tied by the clock, but if you can endeavour to have your say within half an hour that would be good.

**Ms NOLAN** - I can say it in 10 minutes.

**CHAIR** - Okay, I will leave it to you, thank you.

**Ms NOLAN** - I did have trouble hearing the lady who was here before, but one thing I did find quite amazing was that she claimed that most people she talked to said that they really were not happy being donors. I live in Dodges Ferry and every person I have talked to down there has said, 'Well, why not?' It is when they have to think about it. If you are sitting in the dreaded 'green room' in the Royal and there are two specialists there with your son's CAT scan and they say, 'That's it' and you say, 'Well, why not?' We had had 12 days to get used to the idea that he was not going to make it. I think if you can sit down quietly, have a Sunday lunch when you are not threatened by anything, there is no great grief on you, and you can just sit and chat, most people would say, 'Why not? Get some-one else well.' In fact what I have done is a bit cheeky here. There are not enough of these to go around, but there are four copies. This gives the recipient's point of view - it is a copy of the LifeGift showing where Sam's organs went.

**CHAIR** - We spoke with LifeGift yesterday.

**Ms NOLAN** - They are absolutely wonderful. As for some of the assertions that people feel left up in the air, I thought they were just brilliant. Even now, two-and-a-half years later, they have just phoned me up to say, 'We're just checking, are you okay?' They are lovely, wonderful people. The first note is from the heart recipient. You could tell he was a farmer because he used very large letters and they were strung out a bit! The blurred bit is where they have tippexed it out so I immediately got a knife and scratched it off just to see.

**CHAIR** - You could have looked from the other side!

**Ms NOLAN** - I tried that and I still could not see it! That lovely one is from the liver recipient who, the year after he had Sam's liver, was well enough to fly overseas to his son's wedding. So they do not fall over in a dead heap - that is a bit dramatic. That is a

lovely one from one of his kidney recipients. In fact, the surgeons covering his case said it was almost a perfect match, and I thought 'poor man'! He is now driving a red sports car with black daggers down the door!

Anyway, there you are. That gives you the other side of the picture. You can have the technical side from somebody whose job it is to be an informant, but at no time did we feel pressured. In fact, the weekend after Sam's service every organ donor form in Sorell and Dodges Ferry disappeared, was filled in and sent back. He was only 22, but 250 people came to his funeral. They read out that form and everybody just was talking about well, why not.

I know that there is an argument that perhaps some people who need an organ deserve it: the lady who has just left might have a niece who might get cardiomyopathy. That teenager has not done anything wrong but get a virus, and their heart is going to go. I know a couple of recipients - a double lung and a kidney - and they have a terrific take on life. They say I have been given a second chance, I am going to grab it with both hands - not be stupid, but just live life to the full. Not that long before Sam died, I had actually got him to fill in the form. He and his friends were sitting around out on the deck having a Bundy and coke - that was his passion - but his liver was fine, we were just amazed.

*Laughter.*

**Ms FORREST** - He was only 22.

**Ms NOLAN** - At his funeral service Richard, a friend, was absolutely wonderful. He read this out and then he said as an aside that Sam always thought he did not want a nun to get his liver and that brought roars of laughter. That was him, he was a party boy. He went out with a bang, you know, and he has left his legacy, which is great. We were sitting down on the deck and I said, 'You have to get people to think, it is a bit like the Chinese water torture. You have stickers in the back of cars just to keep reminding you, just to keep it somewhere in your subconscious, not down the bottom, not where it is too hard to think about, but something which is gradually drip-fed into you.' Sam said 'What about pass them on when you pass away'. We laughed about that but why not, why not? If he had survived he would have been paralysed. One of our best friends had dropped with an aneurism while doing the ironing. It took Joan two-and-a-half years to die and meanwhile one of her children committed suicide because he could not live without his mum. We didn't have that. We had 12 days. Because I am a nurse I had seen the downside of it. My husband is very practical. In the end the damage was so severe that Sam would never have survived.

**Ms FORREST** - Being a nurse, did you have any concerns?

**Ms NOLAN** - I did my nursing training a long time ago.

**Ms FORREST** - It does not matter, you still have the knowledge. It has been raised in some of the submissions and in the last presentation to some degree, were you concerned at all about -

**Ms NOLAN** - Whether he was really gone?

**Ms FORREST** - Yes, whether he was really gone. We talk about the parasympathetic and sympathetic nervous systems and how they are different.

**Ms NOLAN** - I know. It was dreadful. We were told that he was technically brain dead but if you touched him he moved. I did not find that hard. My husband did not, but my son did. But that was fine; he said his farewells and went away.

**Ms FORREST** - Did your other son get to the point to realise why that was happening?

**Ms NOLAN** - The thing is that two years before my son had made a spectacular job of demolishing a car, driving it on its roof for about 100 metres, and he had massive surgery on his hand. Frank Kimble, the plastic surgeon, rebuilt his hand, but Sam also partly scalped himself because his head was hanging out. I do not feel that he was ever quite the same after that although there was no indication that there was any kind of brain damage on CAT scans or MRIs. He went into that crash 100 per cent but he came out 98 per cent. I think that was more emotional as well. He felt maimed and it was not his fault but that really affected him. That put him into a very enclosed world; he curled up inside himself for a long time and was just coming out of himself when he did this. I just think sometimes it is programmed to do something daft. He was a risk-taker and I think Adam said afterwards that Sam was just so upset about his hand. What would he have been like if he had survived ? It would have killed him.

**Ms FORREST** - So Adam was able to intellectualise it to a certain extent?

**Ms NOLAN** - Yes, it has taken him an awful long time, probably two-and-a-half years, but my husband and I both said you have got to put your faith in doctors, you cannot second-guess every decision they make, otherwise your life would be miserable. You go into Austar when you are doing the ironing or the washing and there is some story about somebody who was in a deep coma and they just got up and walked out the door. That is bullshit. You know that.

**Ms FORREST** - I would like to hear more about some of the other stories.

**Ms NOLAN** - There is always a down side. People say they recovered and then you discover they have had to learn to walk again, talk again and they have no sense of taste.

**Ms FORREST** - Going to the issue of informed consent and getting an appreciation of what informed consent is, how could the current process through Medicare be improved?

**Ms NOLAN** - First of all, I think the way Medicare did that was just useless. How many times have you got stuff from MBF and it is all sort of glossy at the front and you put it in the bin. Then on the back of that is the form saying if you do not fill this in -

**Ms FORREST** - We will not pay you any money.

**Ms NOLAN** - Or we are going to drop you down a level in your repayment system and you do not realise that you have actually done it. I feel it was boring-looking document. It did not get the message over.

**Ms FORREST** - So how should it be done?

**Ms NOLAN** - Education, education, education. There should not be an organ donor week; there should be an organ donor month and I think you should encourage families to have an organ donor Sunday lunch. When you are happy, have had a couple of wines, you say to yourself 'why not'. Sam signed his name on his form but I filled it out because he was dyslexic and he had attention deficit disorder. I said, 'So it is okay that if anything drastic happens' - it was only about six weeks before he did this - 'can we give your organs away'. He said, 'Well if I am dead they are no bloody use to me, are they?' So I took that as a yes and ticked the box.

You see we are a very practical family. We run a business and we have had more than our share of disasters. There are some families where, we all know them, nothing bad ever happens to them and they worry about a broken nail. So when something really bad comes along they cannot work it out. They cannot cope with it so it goes into the too-hard basket. But I think if you make a decision very early on then to me it is just one more process.

**Ms FORREST** - So do you think that it would help if there was a person in the State who was well informed about organ donation and both sides of the argument? Once the decision or consideration was given to organ donation, and someone had to fill in the form, they could then be directed to speak to this person to ensure that they have got all the information they needed. Would that be a useful thing or is that too onerous?

**Ms NOLAN** - Absolutely. I do think education, education, education. I have the LifeGift program here. I go every year.

**Ms FORREST** - To the service?

**Ms NOLAN** - To the service in Melbourne, then meet up with your coordinators. They are just brilliant. Here is a lovely poem from a young recipient. I will leave it with you it is just super and to me it puts it completely in perspective. I think education, education and education.

**CHAIR** - What happened after you were told that your son was brain dead, that he would not make it.

**Ms NOLAN** - I was in the green room by myself awaiting the results of his third CAT scan after his third lot of surgery. They drill rings to release the pressure and Sam had four - the first time that they had ever done it. We waited all afternoon. My husband has retinal problems so he had to go home in daylight. I stayed. They walked in with the CAT scan and they said 'no go'.

**CHAIR** - So they informed you as to that. Did you then say to them, 'I know he signed a document to say that he was willing to donate his organs', or did they come to you and say something about that?

**Ms NOLAN** - No, we sat down with one of the lovely neurosurgeons at the Royal; he was just fabulous. He sat down, he held my hand and he said, 'I think you should get your husband in'. So my husband and my son drove in and I said to him that I think we should go down the organ donor path. I actually said it because I knew that Sam wanted it. We

spoke to the staff that night and they asked if we would we come back tomorrow and fill in the forms. My husband, who is a businessman, has signed more paperwork that we have had hot breakfasts, and he said that he found the paperwork very daunting.

**CHAIR** - Right.

**Ms NOBLE** - Once you make the decision they change the medication regime. They stop preventing swelling and they start preserving the organs. Then we had to wait about 14 hours, which was not as hard a day-and-a-half before the swelling had actually gone down from the front and moved down to the back and hit the brain stem. Then they do two independent assessments. There was no brain activity whatsoever. It was 1 o'clock on the Sunday afternoon and they phoned us and we went back in and said goodbye.

**CHAIR** - What happened when you stated to the doctor that Sam wished to donate his organs? It is always a hard conversation to have, I would imagine, and a hard conversation for the doctor as well. Did the doctor say that he was going to ask you about that or not?

**Ms NOLAN** - No. He was relieved that I brought the subject up first.

**CHAIR** - How do you know that?

**Ms NOLAN** - Just by his body language.

**CHAIR** - I see.

**Ms NOLAN** - I said I have to wait for my husband to come in. So Adam went and said goodbye and then he left and then my husband sat with me and the specialist.

The next day when we went back there was a different doctor there. That lady said that there was no coordination. Well there definitely was because we spoke to probably one of the senior registrars and he went through all the paperwork with my husband. Then we were just about to leave when one of the registrars said there should be a police report. We then had to try and find a policeman, it must have been Sunday afternoon, and that was another six hours - which we did not need. The girl was Scottish and she had dealt with similar things. She said that the Procurator Fiscal in Scotland, which is like the coroner here, would want an accident report.

**CHAIR** - When did LifeGift become involved?

**Ms NOLAN** - When we were saying our last farewells. We had signed the forms, the message having gone back to LifeGift -

**CHAIR** - Why did you have to sign the forms; he had already signed a form?

**Ms NOLAN** - No, sorry, my husband signed the forms. I think my husband then had to countersign the police report, which was a farce because the lass who came had no idea why she was there. It was the only time I saw my husband lose his cool because she kept asking, 'What is his name? How old is he? When did this happen?', so there was a breakdown there - which we did not need.

Then my husband stayed with Sam with one of the doctors sat with him. Then LifeGift phoned me and I was on the phone in the ward for about at least an hour answering questions.

**CHAIR** - You advised them that he had signed the form?

**Ms NOLAN** - Yes, but they did not say to me at any stage that they have to check the records to make sure. The form went in but it was never mentioned again.

**CHAIR** - Did you have to sign a consent as well?

**Ms NOLAN** - Yes, but my husband did that while I sat with Sam, and then we changed over.

**CHAIR** - Therefore it was not only the form from the person, being your son, who wished to donate his organs but it was also a family decision as well?

**Ms NOLAN** - Absolutely.

**CHAIR** - So one of the family at least had to sign a consent form for it to occur as well?

**Ms NOLAN** - Yes, but again we did not have a problem with that and the staff could not have been more sympathetic. We did not need the glitch with the policewoman but that was unfortunate - one of these things that happens.

**Ms FORREST** - Is that a communication breakdown between departments, like between health and police, or within the police?

**Ms NOLAN** - It was a breakdown within the police department because the registrar was on a secondment from Scotland and she suddenly stopped and said, 'No, I think we should not proceed until we have an accident report'.

**Ms FORREST** - Is that normal practice do you know?

**Ms NOLAN** - No, I don't know.

**Ms FORREST** - We could check with someone else.

**Ms NOLAN** - That is right you could.

In fact the policeman who came to take a statement afterwards thought we should have made a report, but no-one else was involved. He was partying with his friends, jumped on a skateboard, tumbled down a hill and cartwheeled. No-one else was involved; it was his own daftness.

With LifeGift, I was probably on the phone for an hour-and-a-half. My husband has a thing about women on the phone. The questions, obviously, were about his state of health, his lifestyle. I didn't edit the truth but I was a bit reluctant to give it all out. He had not been around long enough to do any long-term damage. You could literally hear

ticking of boxes because unless all the paperwork was fine and I had answered yes or no to every single question then the retrieval wouldn't go ahead.

**CHAIR** - What happened with the retrieval process? Did the retrieval team come to Tasmania?

**Ms NOLAN** - Yes.

**CHAIR** - So from the time you spoke with the doctor about it, how long did it take for the retrieval team to come?

**Ms NOLAN** - After we said it was a no go, it was probably about 36 hours for his organs to reach the peak of their condition and for him to have had the two tests to determine no brain activity. We then walked out, which was the hardest thing to do. It was probably early the next afternoon that they said, 'Everything's done and everything went well', and that was it. As far as I know, two Lear jets came down because there was a heart and a liver. I know they got a police escort, although I am not meant to know. I bumped into a lady whose husband was in the next bed to Sam and who had died, and she said, 'I'm sorry about Sam, but it is wonderful that he is an organ donor'. I said, 'How did you know, because it wasn't in the paper?' She said, 'My son-in-law works in the police radio room'. That was fine. For families who have been there, please spread the word.

**CHAIR** - I know it is a tragic time and a difficult thing to get over, but did it make it easier for you that you are a nurse, that you understand the medical procedures.

**Ms NOLAN** - I could see the downsides. When he was first sent to the Royal in an ambulance I was told that it was probably concussion and not to worry, that I would get a phone call tonight to come in and get him and take him home. I took the friend, who had tried to save him, home, dropped my son off, got to the Royal and the next time I saw Sam he was in the resuscitation room on a ventilator. It was 12 days after that. For the first five days they said, 'Wait for the brain swelling to go down'. That is when my husband and I discussed, if he comes home in a wheelchair, whether we get ramps and whatever. Then on about the sixth day my husband said he may not come out of this, and he didn't. The staff are wonderful at letting you down. They didn't say, 'His health is not good'; they used to say things such as, 'He's just not behaving himself' - just gently preparing me.

**CHAIR** - Going through the process, could it have been made any easier for you?

**Ms NOLAN** - No, but I think they could get some better chairs in the Royal and do something about that disgusting Coke machine. We got the phone call about half past one in the morning and we drove in and sat there and we couldn't see the specialist. There is a problem with parents and families hanging around there. You could be there for nine hours and you don't even see a specialist because they were busy with the patient. It used to take two hours to take Sam, his bed and all his equipment, for a CAT scan. You multiply that by 10 people. The staff are absolutely wonderful. I couldn't fault them. You couldn't eat properly, but you were too frightened to leave in case the specialist said, 'Where's Mrs Nolan?' So you sat there all day drinking shitty coffee, and starving yourself. I think perhaps the Royal could have a trolley that comes around with sandwiches just to give you a bit of a lift. Even my husband, who drinks black coffee,

was having sugar in it, and after 34 years of marriage I have never known him to shove sugar. He must have felt rotten, too. But your nervous energy kicks in for sure.

**Ms FORREST** - There's been some suggestion that there should be an organ donation coordinator employed through the Department of Health, or somewhere, to provide a service to educate people to be there when this sort of situation occurs. Two questions for you. Did you have any problems with conflicting advice or information anywhere?

**Ms NOLAN** - No.

**Ms FORREST** - That was not a problem. Do you think such a person being responsible for ensuring you get good coffee and some food is so important?

**Ms NOLAN** - Yes, it is absolutely. You will be driving home and your hands start to shake. You want a back up team, three or four people so there is always one on call or available in shifts to just be a mother hen, really. I walked in one day looking so dreadful, and the cleaner said to me, 'You look like you need a hug', and she just hugged me - it was a lovely thing to do. She tried it on my husband, but he didn't -

**Ms FORREST** - Some people aren't touchy-feely.

**Ms NOLAN** - Not touchy-feely at all, no.

**Ms FORREST** - But if there was someone in that role. Admittedly this only happens on rare occasions, it's not a frequent event.

**Ms NOLAN** - It's sad that it happens on rare occasions.

**Ms FORREST** - Probably it is. Well, yes and no -

**Ms NOLAN** - Yes, and no.

**Ms FORREST** - but if that person could fulfil that role, that would be an extension to the education.

**Ms NOLAN** - Absolutely, yes. I was really blessed that my best friend lived up on the Glebe, so Helen was always there. In the morning, there was only a window of opportunity to see Sam from half past seven to eight. I live at Dodges Ferry and we were still running the business, mining and trucking or whatever, and Helen always used to call in on Sam - it was special. It is the day-to-day grind that gets you down, and I think if you have been through what we went through and not been strong, we might not have been able to make the decision. But I do feel that when you read the letters from the recipients, they are so grateful. One guy says, 'I am really taking care of Sam's kidney, I am running'. That is wonderful. It doesn't have to be the worst thing in the world.

**Mrs RATTRAY-WAGNER** - Nikki, yesterday we heard some terrific evidence, and a lot of it was about discussing what you would like to do if and when that dreadful situation ever arose and you passed on. Would you consider that discussing organ donation with your family is the most important thing that you could do?

**Ms NOLAN** - Absolutely. Just do it when no-one is threatened, but not when you're totally stressed out you are so hungry you could vomit. Honestly. I had a packet of Valium and I just popped them to stop myself being sick. You find yourself driving: I drove out of Hobart and I found myself in Midway Point. I had no idea how I got there, but the stress just compounds itself day by day. But if we hadn't made that decision as a family, it could have been the last straw. You'd just say, 'No, I can't deal with that'. But if you think about it in a quite rational sense, if someone is dead and they are going to be cremated, why not let someone else benefit from their organs?

I had to explain organ donation to my grandson who was just seven at the time, and the only way I could describe it to him was, I said, 'You may have watched a TV show like *Crossing Jordan* or one of these, without really realising. Do you know what a post mortem is?' He looked at me, and I said, 'When someone dies and they're not sure, they have to look inside and see which organ caused them to die. With Uncle Sam, they looked at each organ and thought this is so good we're going to give it to someone else'. And he said, 'That's fine', he was cool with that and it didn't bother him.

The one thing that made my son and I laugh in an ironic sense was that you hear of people, especially with heart transplants, who take on the traits of the donor. My son read it and said, 'Mum, you need to write these guys a letter of apology'.

*Laughter.*

**CHAIR** - Have you any second thoughts about it now?

**Ms NOLAN** - No.

**CHAIR** - What would you say to people - and hopefully it does not happen – who are in the same position as you?

**Ms NOLAN** - If it does just let something good come out of it. What I find amazing is people who say, 'Oh no, I couldn't donate my organs' and yet if you say to them, 'What would happen if your son came in and said, "We've been to the specialist and your grandson needs a liver"', suddenly, flipside. You should not want to receive if you are not prepared to give.

**CHAIR** - You would be interested to know that more than 172 000 people have signed the consent form to donate their organs within Tasmania.

**Ms NOLAN** - I do not think that those forms should just be in Medicare, I think they should be in the post office and in Service Tasmania. A friend said 'Why not have it on the back of your car rego sticker?' If they can tell you you will lose your licence 'just like that' or you could lose your life 'just like that', why not a gentle reinforcement on the car sticker? My husband said, 'Who reads car stickers?' and I said, 'Obviously on the west coast you don't get stuck in many traffic jams' but if you do, you sit there and you look at it and you think -

**Ms FORREST** - You can follow some big trucks for a long time.

**Ms NOLAN** – They are his big trucks!

*Laughter.*

**CHAIR** - Time is starting to run away from us, are there any final questions? Thank you very much for coming along and giving us some first-hand knowledge.

**Ms NOLAN** - I typed it out to demystify the whole procedure. That is what you have to do - education, education, education. Also, I think there is poor advertising - spread the word in a non-interest way.

**CHAIR** - Thanks for coming along.

**THE WITNESS WITHDREW.**

**Ms MICHELLE EATHER WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.**

**CHAIR** (Mr Wilkinson) - Michelle, thanks for coming along to give your submission and then answer some questions. We understand the process you have been through in the last period of time so we know about that and a bit of background. I would just like to advise you that this is being recorded so what you say is being noted down by *Hansard*. If you want to say anything and you want to say it within the privacy of the committee, please let us know that and then we can discuss whether that should occur. We have listed about half an hour for your presentation. I will leave it in your hands as to how you give it.

**Ms EATHER** - Thank you very much. I have actually written a little speech but it is actually not a little one, I have a lot to say and I have an opportunity to say it.

**CHAIR** - Okay, fire.

**Ms EATHER** - As you know, ladies and gentlemen, my name is Michelle Eather and I am a non-directed live kidney donor which, in simple terms, means that I am one of the very small number of people in this country who have altruistically donated my kidney to a complete stranger. It is my intention today to confine my submission to the subject of live donation.

From the outset I wish to make it known that I am entirely supportive of the need to increase the current rates of cadaveric organ donation to equal the best in Australia. As we know, in recent years South Australia has consistently maintained a rate of cadaveric donation twice that of other Australian States and this is what we undoubtedly hope to emulate in Tasmania. Yet let us never believe that emulating the success of other States will be sufficient to satiate the ever-increasing need for organs in this country. It will not. Kidney disease is an epidemic in this country. Every day it claims the lives of more than 40 Australians and every day we add six more people to Australia's dialysis list. The situation will only get much worse. Today only one or two people will receive a kidney transplant. There are just not enough kidneys available, nor will there ever be. No matter how much we would hope to increase our rate of cadaveric donation, even at optimum rates we will always fall short by at least 30 per cent. We are doing far too little far too late and we, as a nation, must look at the subject of organ donation through fresh eyes. There are alternatives to increase our current organ donation rate. I just hope that we will have the courage to finally realise that we must explore these alternatives if we are ever to win this battle.

In 2006, 641 kidney transplants took place in Australia. Cadaveric donations account for 57 per cent, or 368, donations. The remaining 43 per cent, 273 transplants, were from directed live donors. By definition a 'directed live donor' is a close relative or friend of the recipient. For many people the donation of a kidney by a loved one is their only chance of survival yet, despite the fact that live donation accounts for almost half of all kidney donations and that live donations are statistically proven to be the most successful transplant option, our medical establishment has systemically failed to endorse or promote live organ donation in this country. It is hidden from the view and conscience of the public like a shameful secret.

Some years ago I made the decision to become a live donor. Surprisingly, despite Australia's soaring rate of kidney disease, I do not have a close friend or relative in need of kidney. I contacted a number of hospitals around Australia to see how I could make a donation to a person on our waiting lists. Without exception, every single hospital refused my offer without consultation. Non-directed live donation, donation to a stranger, is considered unethical under Australian guidelines, yet I persisted, convinced that Australia would soon catch up with the rest of the world. I researched the international practice of non-direction donation, and in particular within the United States, which is recognised as a world leader within the field. Based on their guidelines, I commenced ongoing psychological counselling and undertook health and fitness plans to ensure that I was in the best possible health to become a donor.

In undertaking this process I quickly realised that the donor is the most important person and must be protected at all cost. There is little point in undertaking to donate a kidney if you are going to be left in an emotionally or physically vulnerable position afterwards. Therefore I was also able to readily identify all that was important to me as the donor to realise from this process. The most important thing for me was that I maintained my right to be self-determining and to fully participate within the donation process. I also decided that it was crucial that I know my recipient. I didn't necessarily need to like the person, just know a little about them. The only other factor that I determined would be blood-typing. Other than that, I had no set ideals as to who the recipient of my kidney would be. Age, gender, race and religion played no part in the process, nor did I personally believe that they should. I just needed to work with a suitable person who was willing to work with me.

Recently a number of Australian hospitals have adapted their guidelines governing live donation to make an allowance for non-directed donors to come forward. Unfortunately the protocols for non-directed donation that have been implemented to date appear to be aimed towards discouraging rather than encouraging donors and appear to be based on a belief that if an individual wants to donate a kidney then there must be something wrong with them and if there is something wrong with them they should not be allowed to donate a kidney.

The process is excessively long - 15-18 months - requires an intense commitment by the donor, is financially restrictive as there is no compensation whatsoever and the donor will be required to take substantial leave from their employment. All donations are carried out under strict anonymity. The donor has no choice who will receive their kidney and, ultimately, all of this is dependent upon the approval of an ethics committee. If the donor finds all of this a little bit too much, then they probably were not suitable anyway but many are still not aware that these programs are available because another stipulation is that they must not be advertised, and they have failed dismally.

I made an informed choice to reject these options and instead chose to donate to a gentleman in the United States. I did so with the full knowledge of the facts and the risks associated with the surgery. I donated at a time that was right for me and to a person of my choosing. At all times I felt that I was in control of the situation and, at all times, I knew that my welfare was considered paramount by the transplant team with which I was working.

At this point, it is probably an opportune time to explore the differences between directed and non-directed donors and how this may impact emotionally on the individual. In the instance of directed donation, it is all too often assumed that a compatible family member will be only too happy to donate to a loved one and all too often undue pressure, whether the real or perceived, will be placed on that individual who has probably never considered donating an organ to anyone.

These facts have been confirmed by leading specialists and no doubt contribute, in part, to the excessive rate of depression of around 30 per cent experienced by directed donors to their loved ones.

For people such as myself, non-directed donors, it is important to realise that we often have no emotional connection whatsoever to our recipient. We have come to understand a societal need and have identified how we might help.

I was fortunate enough to truly like the man that I donated to but I will not sugar-coat the facts. Had it not been Ronnie, it would have been someone, anyone else. The process of choosing a recipient is not unlike choosing a lolly from a lolly jar. There is a kind of detachment that is difficult to describe and indeed may seem somewhat offensive and yet I have heard it from so many others who have done exactly the same thing.

Unfortunately as non-directed donation in Australia is in its infancy there is a tendency by medical professionals to apply the statistical data concerning the incidence of depression experienced by directed donors to all live donors. My research indicates that the prevalence of depression experienced by people such as myself is in fact substantially lower and is more likely to occur as a result of the financial burden that we will experience.

The actual process of choosing my recipient was very straightforward. In late March, I registered my details on an American web site dedicated to matching donors and recipients. The response was nothing short of immediate and overwhelming. The man I chose was the seventh profile that I did. After reading his story I had a sense that I could work with this person so I sent him an e-mail. It was as simple and as effective as that.

My recipient, Ronnie Andrews, is a 60-year-old gentleman from Virginia. He is funny and charming, a loving businessman and can also be a real pain in the neck. He loves sports and shooting things and fishing. He is a doting grandfather and a loving husband. He also suffered kidney failure and had been undergoing daily dialysis for three years whilst waiting for a transplant. He is a real live, loving person, he is not a statistic; and he made the decision to register on this web site just three weeks previously - imagine that. If you wait three years on the national waiting list and then, when you make the choice to be self-determining in your treatment to not be just another statistic, you find your own donor in a matter of days.

After exchanging pleasantries via e-mail, I requested of Ronnie the details of his transplant coordinator and made the initial contact with his hospital. Following their initial screening, I began the testing process to determine my suitability as a donor. The coordinator would e-mail a request for a series of tests which I would then undergo. The results would be forwarded to Virginia and I would receive an immediate update. Every time I received a positive response via e-mail it would be accompanied by a referral for

the next series of tests along with information as to exactly what the tests were for, what was happening and why. The entire process from the initial testing to confirmation of surgery dates took 57 days.

The results of this testing were only ever provided to me in order that if at any time had I changed my mind about proceeding with the donation, undue pressure could not have been exerted by the recipient. And had this occurred the transplant coordinator would have advised him that I did not intend to proceed.

By the time the testing was finished I was totally detached from my left kidney, which testing had shown to be the best candidate for the transplant. I truly did feel that I was just keeping it warm.

The coordinator had such an easy rapport with the donors and provided encouragement and advice at all times. They were very concerned about protecting my mental health but trusted at all times that I knew what I was doing. The choice to donate was always mine and at every opportunity they reinforced that, but had they had any concerns the operation would not have taken place. The surgery took place on 19 July and was a total success.

My recipient is in wonderful health - we spoke this morning - and has returned to full-time work just this week. My recovery was pretty much textbook and after seven weeks I was back to the old me. Psychologically I can see no ill effects. I am neither depressed nor elated. I just feel that I have successfully completed an important task and that it was completed to the very best standard. We are in sporadic contact, which suits both of us just fine. I am often questioned as to whether we do have some incredible bond between us and on a deep level yes, I guess we probably do, but for both of us life has just gone on.

I am not overwhelmed by my gift to him, rather I derive enjoyment from hearing that he has just played his first golf game in three years or about his excitement in his newborn grandson who just 10 weeks ago he feared he would never see. I enjoy hearing that he has been restored to health and that his family has been freed from the shackles of his illness and are once again fully productive, contributing members of society.

It would be very easy to hear my submission and think that I am just one woman who chose to go on this journey. I am not. Currently there are more than 70 Australians registered on one web site alone to donate to American citizens. Another transplant occurred in the US just days ago and I personally am in contact with 23 individuals who wish to become kidney donors. Not one of them is prepared to donate in this country under our existing laws.

**CHAIR** - What do they think should change for that to occur in Australia?

**Ms EATHER** - They would like to see a system very similar to America's.

**CHAIR** - The system in Virginia that you are speaking about?

**Ms EATHER** - Yes. Just to make it more user-friendly.

As the demand for kidneys grows in this country and the Internet becomes more readily accessible, we can expect to see an explosion in the number of patients in need of a transplant heading overseas. Two Australians have surgery dates in the United States, they have found their donors on Internet web sites.

Sadly, I am also aware of a number of desperate Australians who are currently arranging their own transplants courtesy of the Indian and Philippines black market where a kidney can be obtained for as little as \$2 000. We would like to believe that this insidious trade is not happening. Well it is, every single week. Desperate Australians with no other treatment options will continue to take advantage of the poor and the under-privileged, and we have no way to regulate it. The trend towards patients finding their own donors and donors seeking their own recipients will only increase and the more established and unregulated the trade, the more likely it is that Australians will recognise their ability to financially benefit from donating their organs. It can and will happen.

Recently I read the story of an American man who swapped his kidney for the recipient's holiday house. We will bury our heads in the sand at our own peril. If we act on this matter now we have a chance of regulating non-directed donation in this country, thereby ensuring the best possible outcomes for all involved. In reality, the Australian Medical Association is well aware that endorsement of non-directed donations is just around the corner.

The major obstacles we will face is that ethicists in adopting the protocols governing this type of donation have tried to protect and regulate the programs to the point that they have been made unworkable. But who are they really trying to protect with these policies? The donors? Believe me, by the time a non-directed donor makes contact with a transplant team they have a pretty good idea of who they are and why they wish to donate. Perhaps they are ultimately concerned with the recipient. Well my research has shown that most recipients are just truly grateful for the chance of an improved quality of life for themselves and their loved ones who have endured their illness with them. Every cadaveric recipient I have spoken to has stated that they would have loved the opportunity to know about the donor, to have been able to meet with the families and say thank you. I am concerned that ethicists are ultimately more concerned about protecting the medical establishment and I believe this to be the major stumbling block.

At the end of the day, these arguments are quickly becoming less and less relevant. Unless the Australian Government is prepared to invest many millions of dollars into preventative programs aimed at raising awareness of preventing kidney disease, then it is almost unavoidable that we will follow the current trend in the United States and see an explosion in the rate of individuals finding themselves on our transplant lists. As a little aside, current research indicates their problem is around 20 times that of Australia. It is that significant.

A system that encompasses non-directed transplants will eventually have to happen in Australia. Every time a person receives a kidney donation the annual savings to taxpayers is in excess of \$50 000. In accordance with the Bureau of Statistics, if we give consideration that the recipient and their families will be free to become fully productive members of society again, it is reasonable to expect that the saving to the community may be as much as three times that amount.

I wish to state that every medical practitioner that I have spoken to in this country has expressed their support for my decision to donate. Many have stated that a system inclusive of non-directed donation is necessary and ultimately unavoidable, but many of these practitioners are still wary of going out on a limb and publicly declaring support. In Australia we have, without doubt, probably the best and most highly skilled medical establishment in the world. The implementation of concerted programs encouraging of non-directed organ donation is an achievable goal. I can see no reason why programs for altruistic donation cannot run in complement to the amazing works of organisations such as Kidney Health Australia and the David Hookes Foundation.

Any programs we implement must be user-friendly and understanding of the needs and desires of both the donor and the recipient. We need to consider the financial impact to all live donors and introduce a system to compensate for the financial losses of around \$5 000 that they will incur in making this gift. The shortage of organ donations is not new, it has been an ongoing crisis in this country for more than a decade, and yet we persist in constantly trying to resuscitate a dying system. There is no point in continuing to put a bandaid on a gushing artery and hoping for the best. Please let us not be here revisiting the same issues in 10 years' time. It is time to get excited about new possibilities whilst improving existing donations. Let us renew our passion to seek out alternative treatments and practices. We have the ability to save hundreds of lives. I intend to ensure through my business, Living Donors, more and more lives will be saved in this country and I am hoping you will join me.

**CHAIR** - Thanks Michelle. Any questions for Michelle?

**Ms FORREST** - I think we all know we only need one kidney and we are given two to start with. During the process and after you have donated your kidney, has it made you more aware of your own kidney health do you think?

**Ms EATHER** - Absolutely. There is no reason why I should have to make any major lifestyle changes. I do have a very healthy lifestyle now. I have chosen to watch for diseases that may be a possibility in the future - the major contributing factors of kidney disease we know of are diabetes and hypertension. I will always be a little bit more vigilant regarding that, but it is a great way to be anyway. I truly have had no ill effects to date from the donation.

**Ms FORREST** - If I decided to donate one of my kidneys and I gave it to someone who then subsequently abused their health and did not take reasonable measures to ensure the health of what is now their kidney, do you think that would be an issue and would it impact on your decision? Would it make you regret it, do you think?

**Ms EATHER** - It is a good question, but no. For an altruistic kidney donor - and there are hundreds of us, believe me - when we give a kidney we do so with the full knowledge that we are giving a gift to improve someone's quality of life and that of their family also because of the burden that kidney disease places on the recipient's family. It is a gift and they will use it as they see fit. In donating to a 60-year-old man he can probably expect now to live out his entire life with this kidney so there will be no other choice for him.

**Ms FORREST** - Is that sort of issue dealt with during the process of counselling that you received prior to it?

**Ms EATHER** - Absolutely. What he does with it is his decision. I gave it away happily and with my full heart. I have no expectations of what he will do. With the vast majority you will always find that they have a deep and undying respect for that chance of life. We do occasionally hear of people who drink themselves to death after receiving a liver and that does make us go, 'Right, that was great of you', but it was a gift that I gave. I do not own it and I do not own him.

**Ms FORREST** - You cannot give your liver when you are alive, though.

**Ms EATHER** - You can give part of your liver.

**Ms FORREST** - Yes, you can give part of it.

**Ms EATHER** - Yes, you can. It is not something I endorse. The statistics say that we still need quite a bit more work in making that kind of donation.

**CHAIR** - Michelle, what made you make the decision? You said you made it at an early stage.

**Ms EATHER** - I became very interested in organ donation as a teenager. I just saw the greater need. I had researched it for many years and I have been a passionate supporter of organ donation, but in just doing the math - and I work in accountancy - there are not enough organs to go around. It made perfect sense to me. We can do it, live with one kidney and be totally happy. Can you imagine knowing that on the other side of the world someone got up this morning with a smile on their face and enjoying life? That is the motivation for doing it, just to make someone else's life that little bit better.

**CHAIR** - You say within Australia already there are 70 people who are willing to donate their kidneys in America.

**Ms EATHER** - I spoke to the CEO of the web site that I went through just this morning and he now has closer to 100. A lot of that is from the work that I have been doing and the fact that I have had my face splashed everywhere. It has encouraged people to sign up, but that is not the only reason. In addition to that I have 23 that I have been in contact with. We now have three hospitals working towards taking in donors. Yes, we have nearly 100 donors who have actually come forward, expressed a desire to donate a kidney and have nowhere in this country to go at this point.

**CHAIR** - Do you know whether those people have signed the form to donate their organs if they die?

**Ms EATHER** - Absolutely.

**CHAIR** - They have done that as well.

**Ms EATHER** - Absolutely. Just as a little aside about registration to donate, when I went to the United States one of my biggest concerns was that my organ donor card would not be valid there. That actually was a stumbling block. I refused to donate in the United States

unless I could be considered a registered organ donor in Virginia, so I am total body donor. I have a living will that states exactly that; it all goes to whatever can be done.

I actually signed a power of attorney which gave my recipient's wife the ability to act on my behalf should I be in that situation where an organ donation decision had to be made. I cannot see why we cannot nominate a person in Australia, who is aware of our wishes, to have power of attorney, someone you have discussed it with. It could be part of the standard Medicare form that we have. It was very much a power of attorney and there was a full expression of my views on what would happen to me - a living will, literally.

**Ms FORREST** - Do you think that could be achieved through advance directives?

**Ms EATHER** - Absolutely.

**Ms FORREST** - Do you think that would be a way of achieving that in a better way?

**Ms EATHER** - Yes. It is one thing just to have a organ donor card; I now have one in my purse and I am sure most of us here have one. However, it is as useless as the cardboard it is printed on unless our wishes are enforced. That means we must have people who are aware of what we desire for ourselves in death. There is not a person I know that isn't aware of my wishes, but it's a difficult thing for some families to talk about. A living will allocating a person who will have that power to make that choice on your behalf, is a wonderful idea.

I was actually trying to get a copy of the form to bring with me today so that you could see it, but the transplant coordinator has just gone on maternity leave. But I am still trying to achieve that.

**Ms FORREST** - Which form is that?

**Ms EATHER** - The transplant coordinator in the United States. It is a very pretty form, it looks great, it is very user-friendly, and it allows you to tick boxes to express desires and wants. It takes an organ donor card that step further. In handing over power of attorney, if I was declared brain dead then power of attorney would have gone to the recipient's wife and she would have made that choice on my behalf. It is watertight. They have someone else to sign it and it is a legally binding agreement, so there is no way to get around it. It is what it is.

**CHAIR** - This occurred in Virginia?

**Ms EATHER** - In Virginia, yes.

**CHAIR** - Are all states in America able to carry out these operations, or only some states? Do you know how many?

**Ms EATHER** - The bulk do. I think some of the bible-belt states down south still have some reservations. It really doesn't matter because you will find that these people will simply move to another state. I know of two Australians who have booked surgery dates in America. They are prepared to spend a \$250 000; that is what it will cost them

because they will have to pay to get their kidney. The transplant teams over there are amazing.

**Ms FORREST** - Australians going to receive an organ?

**Ms EATHER** - Yes. They are going to receive kidneys; their donors were not happy to come to Australia for whatever reason. Probably because they wouldn't be covered for their health insurance costs. The recipients I believe are both in the United States now, and they have firm surgery dates when they will receive kidneys.

**Ms FORREST** - I am just thinking of the logistics because you are still going to have to have dialysis until you actually receive your surgery.

**Ms EATHER** - Just for me to get the testing process under way, trying to get blood from Tasmania to Virginia within a 48-hour period, is not something I would recommend that anyone ever try. It is all but impossible, but we did achieve it. There are logistical difficulties in donating overseas. I would love to see, as more and more people become aware of these web sites, more and more Australians joining up and registering to become donors. I really want to see that happen in this country, and I think it's unavoidable.

I have actually been asked to address a hospital - I won't mention the name of the hospital because the media is here - and they are actually looking to use these web sites to debate whether or not ethically they should be promoting the recipient, the person in need of a transplant, to be self-determining in their treatment options. So it is an option but a lot of people aren't aware that there are people like myself out there. I was with a nephrologist just the other day, and I spoke to two ladies, one of whom is on dialysis every other day. She had never given consideration to the fact that she could find her own treatment. She didn't think she would be allowed. There are options out there, and people are taking them.

**CHAIR** - Would you rather have donated your kidney within Australia?

**Ms EATHER** - Absolutely. I did try. If you have made the decision to give a kidney, you pretty well know who you are. I am prepared to make a gift as enormous as this. Let's not kid ourselves, it is a painful procedure and I developed an infection afterwards, which did lay me up for a little while. I take responsibility for that; I was so homesick for my children that I flew out before I should have. To have been in control of the process, to have had an equal standing, to have felt it is a huge gift and to have someone say 'You will give it to this person, you will give it to this person when we are ready, and you will not know that person. In fact, we are going to put you in a separate hospital to ensure that it does not happen, that there is no contact', was unacceptable to me. I will make the gift but at least allow me to be part of the process. Take the kidney but let me have an equal standing and be self-determining and to have an understanding of the process and not have it all dependent upon what other people had decided for me. It was not acceptable and I believe the programs in total over the last couple of years have had six, seven donors who have made it through to completion. The programs have failed dismally. They just will not work. Would you be prepared to miss up to 10 weeks of work, not be paid for it, in order to do this and not even know who got your kidney? I do not need the person to say thank you, I still do not. I actually get a little embarrassed

because Ronny gets a little bit excited and says, 'Thank you so much'. I do not need that but it was my right to be able to say 'I will give you a kidney. Let us get to know each other for a little while. Let me have some enjoyment of your enjoyment of what we are doing'. That was really important to me. I will fight. I will continue to fight. It will happen so we do not really have a choice. People do not like being told that they have no choice, but we do not have a choice.

**CHAIR** - Time is starting to march on, Michelle. Thank you very much for your time and for your submission. It was helpful and well put together. All the best.

**THE WITNESS WITHDREW.**

**Inspector PAUL GRAY** WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** - Paul, thanks for coming along to address the committee. As you know, the terms of reference are one to five as set out. We know a bit of your background in relation to your submission and what has occurred but if you want to give your evidence as you think appropriate, no cross-examination until after you have finished.

**Mr GRAY** - We have been there before.

**CHAIR** - We have.

**Mr GRAY** - Mr Chairman, I have made some notes so if I run through that and if you would like to ask me any questions then.

I donated my kidney to my brother Andrew some four-and-a-half years ago and the history of that was that Andrew got a virus when he was overseas about 10 or 12 years ago and over a period of time became unwell. It was some considerable time before it was identified that he was undergoing renal failure.

He developed chronic renal failure about five-and-a-half years ago which resulted in his undergoing self-dialysis and which required two tubes to be inserted into his stomach cavity - Ruth, you would know more about this. They take a solution out, put a solution in and it basically works on the stomach cavity and removes the stuff.

**Ms FORREST** - Peritoneal dialysis.

**Mr GRAY** - Yes.

That was a bit of a shock to him to have to undergo that. As you could imagine, he was a fairly active man and he had two tubes sticking out of his stomach.

He underwent a compatible donor transplant about five years ago and there were complications with that that resulted in removing that kidney and he was in ICU in Melbourne and then in Hobart for some weeks. It was a life-threatening experience for him.

I had determined some time before that that I would consider giving him a kidney and I think in the back of my mind I was thinking well, you will get a compatible donor at some point which will save me that issue. However, when he underwent the transplant and the problems that arose from that it was quite clear that his best chance and probably his only chance of survival was for one of his siblings to provide a kidney. He has six siblings and at that time I was the healthiest and I suppose in the best position to do it so I made the decision to do it.

There are a number of considerations - there he is -

**CHAIR** - He has a smile on his face.

*Laughter.*

**Mr GRAY** - I will have to leave some of this out now.

**Ms FORREST** - We can compare it if you leave it in.

**Mr GRAY** - Absolutely.

I researched it extensively on the Internet and other sources that I had and I found at that time that the survivability of the donor kidney from a sibling rather than from a non-family member increased Andrew's longevity considerably from five to 15 years to 25 years plus. So I researched all that and then I researched the survivability of the donor and felt quite comfortable with -

**CHAIR** - Which one did you research first?

**Mr GRAY** - Both together really. And I needed to ensure I suppose that there were not going to be any lifestyle changes for me as well and I found that to be the case.

I had to consider what would happen if my remaining kidney failed and -

**Ms FORREST** - Ask for it back?

**Mr GRAY** - I think I did at one stage ask for it back and he refused to give it to me.

What would I do then? Would I call on my son or my daughter or my grandchildren to provide that and the determination made at that time was that I would live with that, that I would not impose that on them, so it was my decision and I have lived with it.

I suppose one of the main considerations for me was that I would not then be in a position to provide a kidney donation to my children or grandchildren should they need it. That was probably the main issue for me to get over. There is a nine-month preparation for the surgery. There were extensive blood and tissue tests. I underwent an angiogram that was quite horrific and at that time - that is when they put the dye through and I could actually see my kidneys on the screen and they gave me some photos of the two - they found that my left kidney had two arteries in it so they could not transplant that. The keyhole surgery at that time could only be done with a left kidney they had not developed a process for the right kidney so I could not have keyhole surgery and they had to open my abdomen right up. So that was another issue for me at that point. But I had gone that far down the road that it did not matter what they were going to do. I had 10 days in hospital and a three-month recovery. That had an effect on family and work.

The operation was expensive for the community to pay for, but the ongoing costs in Andrew's non-requirement for dialysis and all those sort of things balanced that. The same situation occurs with cadaver donation. If it is successful then the ongoing medical costs for the recipient are greatly reduced. That is a consideration for government to make in relation to framing legislation to do it.

I have considered the opt-out option that has been suggested. While that has significant social applications and it will be, I suppose, a hard fight to get that through, it will significantly increase the availability of cadaveric organs. In that issue the matching of

tissue and blood types is not as important as a lot of people think it is and I am sure that you have had advice from physicians in relation to that. You do not have to be an absolute perfect match and it will greatly decrease the number of people that will have to go through the process that I have gone through. So people are not going to have to go through that consideration and assessment that I did – and, indeed, through the surgery. So I would support an opt-out option.

**CHAIR** - Paul, you were able to donate your kidney to Andrew. We have heard already over the last day and a bit that if I wished to donate my kidney, I would be unable in Australia to donate it to a person whom I deemed should be the recipient. Did you have any problems with that? Has the law changed or alternatively are you able to donate to your family?

**Mr GRAY** - I do not know what the restrictions are in relation to non-family donations. My understanding is that if you want to do that then you can do it. But I think it is about identifying particular persons - I am not sure. There were no issues for me - none whatsoever. There are lots of assessments done through that nine-month period to identify that I was on the right track and that I could cope with it and all those sorts of things. That was quite extensive.

**CHAIR** - The previous witness just wished to donate her kidney and she was unable to do that in Australia and therefore had to go to America to do so. She wanted to have some say as to where that kidney went and play some role, as opposed to otherwise.

**Mr GRAY** - I do not know what those legal restrictions are. But I certainly did not experience it and I do not know whether those restrictions still apply, if in fact they did.

**CHAIR** - Okay.

**Ms FORREST** - Just to go slightly off your story for a moment, I want to return to something that a previous witness said - the lady whose son donated his organs. She said that in the hospital setting - I do not know if you have ever dealt with this personally but you may be aware - there was a bit of a hold-up when they had signed the paperwork. They were hoping for his organs to be taken and used for donation but they had to wait on a police report. He had a skateboard accident, was brought into hospital and was in hospital for few days. When they made the decision there was hold up which they found very frustrating and a bit of a pain really. Are you aware that before an organ donation occurs that a police report is normally a part of that process or not?

**CHAIR** - It was an accident report.

**Ms FORREST** - Accident report, sorry.

**Mr GRAY** - I would not have thought they would need to wait for that. There would be some issues for the Coroner but the Coroner is not involved until life is pronounced extinct. The police involvement up to that point would be in relation to the accident and being aware that that person might die or is brain dead or whatever. I do not know what the hold up would be with the police.

**Ms FORREST** - I just thought you might have known but that is something we can ask other people. Going to the point you made about supporting an opt-out option, we have had varying views on that over the last couple of days. One issue that has been raised in the opt-out option is the difficulty in getting informed consent. Do you think that could be an issue with an opt-out option?

**Mr GRAY** - That will be your primary issue - that if Parliament decided to go down that road it would be about the fact that you are taking away that option of consenting. People would presume the consent unless otherwise. To me that is the hurdle.

**Ms FORREST** - Do you think Tasmanians and Australians would accept that?

**Mr GRAY** - The majority would. I think the majority of the community would accept that. People do not like to think about it. One of the issues that people have is that if I am in Intensive Care they might not do that extra little bit to keep me going and all that sort of stuff, which is absolutely rubbish.

**Ms FORREST** - They do wonder about the expectations of medical ethics and doctors' commitment to their task – we have heard that comment.

**Mr GRAY** - Once a decision is made to turn the switch off then they should be able to take the organs. You have obviously had evidence from physicians, but the time span for kidney transplants is quite long. It is not a matter of taking the kidney immediately from a cadaver. I think it is something like two-and-a-half hours, which is quite a long time before it starts to deteriorate. It is probably not the same case with lungs and that sort of thing.

**Ms FORREST** - You can keep them going a bit longer these days with new techniques they tell us.

**Mr GRAY** - It is probably about that car accident where someone is killed straight away that you have got some considerable time really to get them to ICU to take the kidney. If that was the case, if we had a situation where that could be done it would not be such a big job to identify where the recipient is, which may well be here and they could almost do it straight away rather than having to ship it off to Sydney or Perth.

**Ms FORREST** - So do you think some of the delays occur and we miss some opportunities there because of the time taken to notify the family and for them to give their consent?

**Mr GRAY** - I am sure there would be. If you have a road accident or a shooting victim and you have that two-and-a-half hour time span - and it may be longer now - the thing can be put in motion straight away. The way it is now you just would not do it because the organs deteriorate quickly and you would not be able to get the approval and all those sorts of things to do it. Does that make sense?

**Ms FORREST** - I hear what you saying. I thought you were talking about once they were taken from the cadaver or from the person and then being shipped. But you are talking about a different time from when the accident or the incident occurs to when you can get them hooked up to life support to keep the organs oxygenated and in a healthy state.

**Mr GRAY** - If we had a situation where the person has died in a motor vehicle accident or whatever then the process could be implemented while that person was being transported to hospital. It would happen every time rather than when we found that this person has agreed to donate organs.

**CHAIR** - Paul, when you decided that you were going to donate your kidney, do you believe you were given all the advice that you needed by doctors and any staff associated with the medical profession in relation to what you were to expect, how you might feel, how big the scale was going to be - in other words, filling you in extensively as to what was about to happen?

**Mr GRAY** - Absolutely. I noticed on the news last night that you heard evidence from Matthew Jose. Matthew was a physician at the Monash Medical Centre where the transplant was done and he instilled me with absolute confidence. The surgeon was brilliant. I had psychiatrists, social workers, whatever, beforehand. The post-operative care was absolutely brilliant. I was certainly made fully aware of what all the possibilities were and was fully briefed on that.

**CHAIR** - What about afterwards?

**Mr GRAY** - Yes.

**CHAIR** - In other words, the briefings that you had prior to it occurring were they consistent with how you felt afterwards and how you have recovered?

**Mr GRAY** - Absolutely.

**Ms FORREST** - I will check this with your brother when he talks to us, but they say the operation for the donor is more onerous and more difficult to recover from than for the recipient. Would you say that is a fair comment?

**Mr GRAY** - Absolutely. You can talk to Andrew about this. It was one of the things that sort of upset me a little bit because Andrew was up and about very quickly and grumping and moaning and carrying on and I was flat on my back in extreme pain and thinking, 'Why did I do this? Does he really deserve this?' In fact that played on my mind for some little time.

**Ms FORREST** - Were you prepared for that, though? Were you actually informed that you would be worse off than he was for the first few days or a week?

**Mr GRAY** - Yes, but that is something that goes through to the keeper. I have had surgery before but nothing like this. They put an epidural in and the surgery was on Thursday. On the Saturday the surgeon came around and I was feeling pretty good and I said, 'I can go home tomorrow, can't I?'

**Ms FORREST** - You still had the epidural in at that time, did you?

**Mr GRAY** - Yes, I did. He said, 'No, probably Monday or Tuesday. We'll take the epidural out today and we'll see how you go' and they took the epidural out and I hit the wall. It

was unbelievable and I was worse then than what I was the day after the surgery. It was shocking, absolutely shocking.

**Ms FORREST** - Do you feel that you were perhaps not prepared enough for that?

**Mr GRAY** - I was, but it is only words. You cannot describe pain.

**CHAIR** - And I suppose you think you are able to cope with it as well, don't you?

**Mr GRAY** - Yes, she will be right. But, as I said to Paul before, it was so bad that each day I could feel that I was better than the last.

**Ms FORREST** - That is encouraging.

**Mr GRAY** - It is but it is fairly bad pain when you can feel that difference.

**Mrs RATTRAY-WAGNER** - I guess it is fair to say that it is a good thing that your brother looks so well then.

**Mr GRAY** - He is probably healthier than I am.

*Laughter.*

**Ms FORREST** - I hope he came and sat beside your bed and was very sympathetic.

**Mr GRAY** - No, he was not.

*Laughter.*

**Mr GRAY** - Andrew was recovering and he had his own problems to look after.

**CHAIR** - What about your children and your family? Did they find it hard at all and did you have to go through extensive conversations with them?

**Mr GRAY** - I think that they required me to satisfy them that I knew what I was doing basically and once I had done that they were very supportive of it. I think the bottom line was that Andrew would be dead now if I had not done it really and someone had to do it. I do not think it was a situation where we could have waited for a cadaver donation at all.

**Ms FORREST** - That had been tried and failed on one occasion anyway.

**Mrs RATTRAY-WAGNER** - In that particular case, Paul, would that have put Andrew to the bottom of the list, so to speak? I might have to ask him.

**Mr GRAY** - Andrew would probably answer but I would say yes; in fact I do not know whether he had gone back on the list again.

**CHAIR** - Thanks, Paul. Any other questions to Paul? Thanks for coming along, Paul.

**THE WITNESS WITHDREW.**

**ANDREW DOUGLAS GRAY WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.**

**CHAIR** (Mr Wilkinson) - Andrew, thanks for coming along. As you know, we are talking about organ donation. We have just heard from Paul in relation to him being the donor and his brother - you - being the recipient. You are about to tell us the story as to circumstances behind that in relation to this inquiry. I will leave it to you to give us a brief overview and then, if necessary, we can ask some questions.

**Mr Andrew GRAY** - I will go through the history of the whole episode. From about 1992 I was told that I had kidney disease. For about seven years I was on a drug regime to keep it under control but eventually I went into what they call end-stage renal failure in 1999, which meant I had to go onto dialysis. Initially I was on haemodialysis through the neck, which is an emergency procedure. Whilst I was being operated on for that they did another operation for a more permanent catheter coming out of the neck and a catheter coming out of the peritoneum. When that worked itself out, they then put me onto a peritoneal dialysis regime, which meant doing dialysis four times a day, which you can do anywhere which was a real bonus. I did a 19-day caravan tour of New Zealand doing it, which was rather interesting. You nearly needed a trailer to carry the boxes of stuff with me, but that was beside the point. When that failed in January 2003 they were about to do a fistula operation, which was the haemodialysis treatment, and I got the call to Melbourne.

**CHAIR** - When were you first put on the list of being a recipient?

**Mr Andrew GRAY** - In December 1999. I went into failure I think it was either the last day of August or 1 September 1999. They came over and did interviews and brought some stuff and in December they were ready to take me. They had done all the testings and those sorts of things - blood test, tissue test.

**CHAIR** - So you had to wait until 2003 before one became available?

**Mr Andrew GRAY** - Yes.

**CHAIR** - As to the process of waiting, how do you feel whilst you are waiting? What emotions do you and your family go through?

**Mr Andrew GRAY** - Phone ringing is not a good idea because it could have been every phone call that I ever received was the call. The one I got just came out of the blue and it was probably about half past seven on a Saturday night. We got to the airport and the Flying Doctor Service took us to Melbourne. We arrived just after midnight and they operated at 5.30 in the morning. Unfortunately the kidney did not take, so it was back onto dialysis.

**CHAIR** - Was the kidney not taking a common occurrence, or was it a rare occurrence or does it happen on occasions?

**Mr Andrew GRAY** - I would probably have to say the rest in private if that is possible.

**CHAIR** - Yes, sure.

**Mr HARRISS** - Do you want to do that at the end, Mr Chairman?

**CHAIR** - All right. Would you rather do that at the end?

**Mr Andrew GRAY** - Yes.

**CHAIR** - The emotions that you go through though it is obviously hard on yourself. Is it hard on your family as well? Do you become grumpy as Paul was saying?

**Mr Andrew GRAY** - Did he say I was grumpy?

**CHAIR** - No, that is after the operation.

**Mr Andrew GRAY** - I think what I tried to do was to try to live normally as much as I could. Obviously doing dialysis four times a day and then when you do the haemodialysis of three days a week for six hours basically it almost takes your life away. During that time I started a business of my own and worked when I was not being treated. Obviously now it is full-time; before it was basically part-time.

**CHAIR** - Were you in pain?

**Mr Andrew GRAY** - I do not remember any pain. The only time I had pain was when I got peritonitis and that was only the once luckily. It happens quite frequently apparently with peritoneal dialysis, but I was lucky.

**CHAIR** – So you had a three-year wait, approximately, the kidney was donated that did not work so you were back on dialysis that is where we are at?

**Mr Andrew GRAY** - Yes, that is right.

**CHAIR** - What happened after that?

**Mr Andrew GRAY** - That is part of the other story but I was at a very low point and Paul decided he would give me the kidney. We had the transplant in January – so it was nine months before then.

**CHAIR** - So it was nine months before then that Paul stated that he was willing to donate the kidney. Did both you and he have to go through some processes then to make sure that there was a match?

**Mr Andrew GRAY** - Yes.

**CHAIR** - Did you have to go through any more processes or they already knew that there was match because of previous tests they had done?

**Mr Andrew GRAY** - No, I had to do basically the same stuff.

**CHAIR** - Did you?

**Mr Andrew GRAY** - Yes, because of the other transplant there were antibodies and all that sort of stuff.

**CHAIR** - Did you know well before the operation that you were going to have it at that time or did it just become available?

**Mr Andrew GRAY** - It was originally going to be in November, I think, then I got sick and they put it off until January.

**CHAIR** - So originally November but because you were ill it became January?

**Mr Andrew GRAY** - That is right.

**CHAIR** - You had to go to Melbourne for it to occur?

**Mr Andrew GRAY** - Yes, and we had to fly over to Melbourne beforehand again to do more testing and blood testing. Then we flew back over again.

**CHAIR** - Were the processes that you went through described to you prior to the operation occurring?

**Mr Andrew GRAY** - Yes.

**CHAIR** - On both occasions?

**Mr Andrew GRAY** - Not on the first occasion because it was such an emergency. The kidney had been out of the body for probably nearly eight or nine hours in the first instance which was probably half the reason why it did not settle anyway. The second time around everything was explained and basically it is a pleasure to go there, particularly to Monash. It was everything I expected a transplant to be if you can have such a thought but it certainly was not like the first one.

**Ms FORREST** - Do they do psychological assessments and support, seeing that families can always have their idiosyncrasies, to ensure that it was not going to create some sort of problem within the family later on? Is that a thing that is considered during the process?

**Mr Andrew GRAY** - It was not discussed like that but, because of the result of the previous one, I was certainly tested on how I would be able to cope with the new situation.

**Ms FORREST** - So you felt that support was adequate?

**Mr Andrew GRAY** - Yes.

**CHAIR** - After the operation, can you give us some idea how you recovered and how it has assisted your day-to-day way of life.

**Mr Andrew GRAY** - As Paul said, I think it was a Thursday on the Friday they had me up walking around. That is part of the process, to get your body moving, to make sure things are working properly. You had to carry a fair bit of equipment around with you to

start with, which was a bit annoying. I was out of the hospital within seven days. We moved into a flat across the street from the hospital and I had to go across every day to the clinic. And that went on for a month.

**CHAIR** - That was a hospital flat?

**Mr Andrew GRAY** - A hospital flat, yes. I had to go in every day and they would take blood samples and tests and all that sort of stuff and after about a month and I flew home. I was going to see Geoff Kirkland every week for a couple of months and it has gradually extended out now to about six months.

**CHAIR** - Are you taking any medication now and do you have to take that for the rest of your life?

**Mr Andrew GRAY** - Indeed. It started off with about 56 tablets a day.

**CHAIR** - Fifty-six?

**Mr Andrew GRAY** - Yes, at various times. Now it is down to about six at various times of the day.

**CHAIR** - There is the obvious change that you are here to give us your evidence today and you would not have been without the kidney, but how else has it assisted your lifestyle?

**Mr Andrew GRAY** - When I was on dialysis I was alive but not living. I think that in a nutshell is how I felt, that I was just biding time. But now I have the kidney I am alive, I can work, I can travel, I can be president of the HIA and all that sort of stuff. I could not before. I am still working with my business and it is going very well.

**CHAIR** - And what business is that?

**Mr Andrew GRAY** - An architectural design business.

**CHAIR** - And your family, of course?

**Mr Andrew GRAY** - It was pretty tough for about four years, but things are great now.

**Ms FORREST** - Has your family more aware of organ donation generally and would they be advocates for it?

**Mr Andrew GRAY** - My wife would be.

**Ms FORREST** - Do they discuss it with other people or not?

**Mr Andrew GRAY** - It does not get talked about that often. I think to live normally afterwards you tend to put it back there and I do not dwell on it. The only time I think about it is when I have to go and see the specialist - and that is tomorrow.

**Ms FORREST** - In your submission you said you think an opt-out rather than an opt-in scheme for donation should be considered. The issue of informed consent has been

raised; if people are going to give consent, or withdraw consent, it needs to be informed. That is one of the concerns that has been raised; with an opt-out situation you cannot really have informed consent, or can you? Do you think there could be a problem with it?

**Mr Andrew GRAY** - I think it is a bit like the driver's licence; you are given a chance to opt in or opt out, even though it is probably worthless now, or so I have been told. Medicare hold the only donation register that is viable; the driver's licence list is not considered anymore. If it is marked on your licence and you do tell your family or wear a bracelet like this then I think it can work.

**Ms FORREST** - So do you think that education is more the thing?

**Mr Andrew GRAY** - Absolutely.

**Ms FORREST** - What would you suggest would be the best way then to educate people and make them more aware and perhaps at least consider it.

**Mr Andrew GRAY** - Obviously advertising, and probably hearing from people like myself or Paul or others who have gone through the process, who have either given or received.

**Ms FORREST** - Do you think that every year we should have one day dedicated to organ donation? We have pink ribbon day, and police badge day for remembering police that have died in the line of duty, or does it need to be an intensive campaign for a month?

**Mr Andrew GRAY** - I think it needs to be ongoing because obviously people are dying and being born and all those sorts of things. Obviously you really could not do it until you reached an age where it is legal - 16 or 17 or something?

**Ms FORREST** - You can make an intent at 16 and consent at 18.

**Mr Andrew GRAY** - At 18, so that is when things are done properly.

**Ms FORREST** - So you think it would need to be not just a one-off promotion about organ donation; it needs to be on a regular basis?

**Mr Andrew GRAY** - I think so, yes.

**CHAIR** - Andrew, we have got to the stage where, as you were saying, you would not mind if we asked you questions in private. We have got to that stage now and that being the case I ask everybody to leave the room for a short time whilst we are asking questions in relation to the situation, though you may be happy for Paul to stay.

**Mr Andrew GRAY** - Yes, he knows the story anyway.

**Mr ROLF RUDOLPH SYPKES** WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** (Mr Wilkinson) - Thank you for coming along and thank you for your interest in the organ donation inquiry. The way we are giving evidence - as you probably know it is going to be transcribed unless there is evidence you want to give in private. That can be considered and nine times out of 10 agreed, but if you want to give a general overview first and then we will ask you some questions.

**Mr SYPKES** - Great. I will be brief both for my sake as far as getting oxygen and for your sake.

**CHAIR** - If you want to rest at any time please let us know.

**Mr SYPKES** - Thank you for the opportunity to appear because it is certainly something that has been at the centre of my life for the last couple of years. I am here really as someone who needs a lung transplant and, if it does not happen relatively shortly, then things are not looking too good.

Just by reference, I was originally diagnosed in November 2005 with idiopathic pulmonary fibrosis, which is basically a hardening of the lungs to a point where you cannot expand them or contract them and therefore you cannot get oxygen in and therefore you die basically. One of the rotten parts about this disease is that you lose your voice because of the lack of volume of air coming out. There are also crazy little things that happen – your fingernails turn and all sorts of things.

**CHAIR** - You were diagnosed 2005 and it is an aggressive disease, is it not?

**Mr SYPKES** - It is and there is no treatment, there are no drugs, there is basically nothing. It is just a matter of when you have it it is then in God's hands how long you are here. Other than about one in 10 is successful with a transplant. It is only about one in 10 that end up having a transplant because there is such a shortage. I will just go back to my little bit. I was diagnosed with only about 60 per cent lung capacity and about 50 per cent of what they call transfer - the transfer of oxygen from your lungs into the blood stream and of course from there it goes round your body. In the 22 months since diagnosis my capacity has dropped from 60 to about 50, so that is not too bad a drop, but my transfer has dropped from just on 50 to 30.

I am now really getting to a point where it is almost a critical level. I was not scheduled to go on the list till about October but back in July and August I was losing about 1 per cent a week and that gets very scary. So they said, get on the list now because once you are on the list there is about a one in three chance of getting a lung. A third of the patients while they are on the list, because of the immunity suppressions you are on, get a cancer or other diseases and that immediately means you are off the list. Another third die while waiting or become too old and then die and a third are the lucky ones. Of that third the average life expectancy afterwards is another five years but there are many around that have had 10 years. Whichever way you look at it, it is not a be all to end all. The Alfred, which is where people from Tasmania, South Australia and Victoria go, has a list generally of about 80 recipients, or hopeful recipients,

**CHAIR** - These are for lung transplants?

**Mr SYPKES** - Yes, for lungs and about a third of those will over time get a lung which is great. The timing of course is everything and that is one thing when there is not a big supply. As time goes on my lungs are shrinking. I have actually lost about 5 centimetres in this time. In the meantime your diaphragm grows and your chest becomes a bit smaller, so as time goes on the lungs I need are getting smaller, not that I need them I would like big ones, but only small ones will fit in. That is just one of the changes that are occurring, but at this stage I am only needing one.

**Ms FORREST** - You mean only one lung?

**Mr SYPKES** - At this stage, if it is a really good one, one will do. That of course means if there is a pair of two then they will be able to help two of us. They say that out of the 80 patients on the list every lung that becomes available is only suitable for about three people because of blood type, tissue type, size and a whole lot of other issues addressed to it, so it is still a pretty minimal number. Of those three, let us say, that are suitable, they then look at them individually and ask who is the most desperate and yet still likely to survive. That really means that every transplant patient is desperate by the time they receive a transplant, absolutely desperate. If we could get to a point where there was a bigger supply available we could hit this thing earlier.

**CHAIR** - If you hit it earlier does that increase your chances, first, of your success, and second, an increased lifespan? As you have said, the average is five years and it can be 10 years.

**Mr SYPKES** - To be honest I am not sure. I would assume it would have a big effect going in because you would be so much fitter. One of things is to try to keep fit so that when you have your operation your recovery is going to be good. Once it gets harder and harder to breathe, then your fitness goes down dramatically. Then you have to eat a bit less and then you lose legs and backside like I am.

It has been a real shock to me to have it happen but it has also made me realise because up until then I was not a donor. It was one of those things that I intended to do one day when I got around to it. That is what I am finding with a lot of friends and acquaintances - that now they know somebody who is really in need, it is registering; I had better do it, yes. It is so simple now and there is immediate coverage around the country, not just in Tassie, so it is a great system.

One of the downfalls from what I understand in Tassie is that because there are so few donors the hospitals are really not equipped to handle it. Many of the emergency staff, from what I understand, just do not have the skills or the knowledge. In Australia last year, according to Professor Haydn Walters - and unfortunately I do not think he will be appearing because he is away - there were only around 200 donors in Australia but they were able to harvest about 600 organs. But that is still a minute amount. If that is 200 donors we are what, 2.5 per cent of the population, so in Tassie maybe four or five and that is not really many to get any sort of experience, any sort of system in place.

**CHAIR** - We are told that we have more than 172 000 people who have signed the willingness and the consent form to donate.

**Mr SYPKES** - In the State?

**CHAIR** - In the State, which is an extremely good -

**Mr SYPKES** - That is great, that is good.

**CHAIR** - We are told 42 per cent of the people that are able to do that but then when you look at the actual donors I think there were four last year.

**Mr SYPKES** - Okay, right. I have brought some forms along just to make sure that everybody here has the ability to register if you have not registered yet.

**Mrs RATTRAY-WAGNER** - I got mine yesterday.

**Mr SYPKES** - Oh good, excellent, well you are in. If I might pass those over, Mr Chairman. We never miss a chance you see.

**Ms FORREST** - That is one way of promoting it, obviously giving it out here to people you meet and your friends and that sort of thing. Do you think there is another way though? Not everyone knows you or has come across your path.

**Mr SYPKES** - Sure, sure.

**Ms FORREST** - And it is not something I would think to talk about just out on the street. What other ways do you think there could be of really raising public awareness, how often should it be done and what should we do?

**Mr SYPKES** - Certainly in my view there is no better way than somebody individually talking one on one because then you can cover the bases well. It is a problem to get out there in the public arena, but I think there are great opportunities through organisations such as Rotary, Lions, Legacy and the different services groups. First of all, they are generally looking for speakers and, secondly, they are generally people who want to help society and want to become involved. Certainly in my experience, once one of the family members has signed up it does not take long before the whole family to sign up. Again, one of the big things in any marketing, I believe, is it is essential to tell your family what you are doing. The last thing I think any of us would want is if the situation arose and you were about to have an organ taken but your family did not know. I think that would be very traumatic.

**Ms FORREST** - Do you think it would help having an annual organ donation day much like the other days we have for breast cancer and the Jeans for Genes day?

**Mr SYPKES** - It would make a difference so it is always worthwhile. A big thing though I think is still to get people to actually sign on the line. Many people I have found will happily and freely take a brochure, and say they will do it. I find the best thing is to say, 'Okay, if you want to do it, let us do it now. Let us fill it out now, sign it now and I will even post it off for you.'

**Ms FORREST** - So do you think that is informed consent then? I am just being the devil's advocate here.

**Mr SYPKES** - It comes with a brochure and when you are registered, Medicare send a little card. On there they stress a couple of things such as talking to your family and so on and you can change that if you wish to. If you wish to withdraw you can do. If you wish to nominate only certain organs you can do. Informed consent, maybe that is a bit of bullying tactic on my part, but people generally have got their own mind. The whole issue of opting in or opting out has been interesting. I think possibly because of people knowing my situation, in the many people that I have asked about this matter, I have come across only one who has said, 'No I would not like to see an opting-out system. Only one out of many that I have asked, albeit that I know that they would empathising with me in that area. There seems to be a logical support to at least consider being able to opt out of it as distinct from now opting into it.

**CHAIR** - It has certainly created debate and interest which is an important thing.

**Mr SYPKES** - In Spain for instance they have the opting-out system and there if you need a lung you can almost get it off the shelf. Not quite, but there is such a turnover that there really is no waiting. The whole health system is saved all that delay in time - two or three years of constant care that I have now had as far as regular visits for tests and more tests, monitoring this, monitoring that. The Alfred transplant team come to Hobart every three or four months to do a clinic. There is a huge cost in all that.

**Ms FORREST** - So do you think the Spanish model that you mentioned has any other aspects that may be able to be implemented in Australia and in Tasmania that could enhance availability? The opt-out system is what Spain has, but the relatives still give consent.

**Mr SYPKES** - I do not know their whole system there. All I know is that it is an opting-out system and that basically organs are therefore readily available. I do not know anything else about the system.

**Ms FORREST** - We have had evidence to suggest that in Spain, and certainly in South Australia, which is based on the Spanish model, there are coordinators in each of the major hospitals. In a State the size of Tasmania you would not need to have one in all hospitals possibly, but the role of that person is to inform and educate the public and educate the medical staff. You made the comment that the DEM nurses and medical staff are not familiar and they do not have a lot of exposure to this situation. Do you think that is an important part of enhancing public education and also the education of the staff and should we really push for that sort of thing?

**Mr SYPKES** - Unless there is somebody pushing it, or an organisation pushing it, it is not going to go anywhere. The whole coordination to me is critical and the whole understanding of this is critical - understanding of what really are the needs and what really are the demands. That will involve training and to have somebody who is coordinating all those areas would be a big job. It would be a terrific opportunity and a terrific way of consolidating all the bits and pieces that are happening, and promoting them. Every aspect needs to be looked at. There is no point in just having more donors; we have to be able to harvest them successfully. I know that it is a horrible word, but we

need to be able to harvest them because we do not want donors available and then organs being wasted. So education all the way through, and somebody focussing on it, would be phenomenal.

**CHAIR** - Rudi, your lifestyle obviously changes as a result of the illness that you have. You cannot be as active and you were more than active previously, so how has it affected the family? What I am looking at are the obvious benefits that people cannot see unless they are actually living through it.

**Mr SYPKES** - One of the biggest concerns for the family is that we are all living with the potential that, because of the stress on the heart created by the fact that there is not enough oxygen, one is more prone to a heart attack and prone to a lot of other things. I am prone to a lot more diseases because of the suppressants that I am on. So the family are living with an unknown and that concern and that is affecting everybody. On the positive side it has brought us as a family much closer together because if there is a problem in the family we rally around it. I will not say that their own lives have been put on hold. For instance my son is currently in America to do his MBA at Stanford and he really would like to be here with the family at this point. Fortunately we can get him home within three or four months so that compensates a little bit. But his whole life over there is on edge because if he gets a phone call at 3 o'clock this afternoon he wants to be on the plane at five past three. So his life is on an edge. My son in Melbourne is working over there but he now comes over every two or three weeks because he just wants to spend time with us. The most affected is Beth, my wife, because she sees me decreasing in my ability to move, huffing and puffing, not able to do things. Life in some of the rooms at home is not as active as it used to be.

**CHAIR** - So you have a remote control now rather than getting up to change the channels.

*Laughter.*

**Mr SYPKES** - Something like that, yes. It is a whole lot of little things. I can put out the garbage but I have to do it very slowly. The silly part is that so often I forget that I am a bit short of breath, so we just race around as normal and then five seconds later I will be out of breath totally. So I am having to slow down with everything.

**CHAIR** - What about your state of mind? Is your illness something that is more likely to occur in your children because of genetics?

**Mr SYPKES** - That is an interesting one. I would be happy to address that but I would rather do it without the kids around.

**CHAIR** - I understand that. We might move onto that at some later stage if that is all right.

**Mr SYPKES** - Yes.

**Ms FORREST** - If you had an organ donation day, or a week or a month or whatever, do you think those people are more likely to come to the fore and say, 'I am one of these people'?

**Mr SYPKES** - Without any doubt. There are a number of recipients out there more than willing to stand up and be counted. There are a lot of good stories out there. I do not know of any recipient that is not over the moon. Not everybody survives but for those that do I think there are a lot of positives out there and the best people to talk to about the positives are the recipients.

**CHAIR** - Rudi, I was a person who said yes and I have no problem in donating my organs but I did not get around to signing the form until a couple of months ago. A number of other people, I believe, and the majority of people I have spoken to, are the same. Therefore in order to get those people to actually sign the form something has got to be done. It has got to be out there in the public notice. What we are doing now may assist but also there has to be an education process to tell people what it is all about. You have stated that ways of doing that are by people talking about it. The button day as mentioned by Ruth is probably a good idea because it is another way of getting people to debate it. Are there any other ways we can properly educate society in relation to organ donation?

**Mr SYPKES** - I think you raise awareness of it through the media. I am not convinced that you get signatures because of that increased awareness. My experience has shown that so much is from personal contact, a personal request, a personal suggestion. To promote the issue of organ donors in the media highlights and lifts the whole profile, as does an organ donor day. Then people are much more prone to be happy to sign up.

**Ms FORREST** - I guess the other thing too is making it more a part of everyday thought. We had a lady appear today whose son was a donor. The fact that they had already thought about it and had a discussion made it much easier. If it becomes part of regular discussion, even if it is in public not necessarily in the family, at least it is out there. Just having it out there will make it easier for people to discuss it.

**Mr SYPKES** - Certainly it does.

**Ms FORREST** - It does not make them sign up, I agree, but it might make it more an accepted thing to talk about.

**Mr SYPKES** - That all has to help, without doubt. If they are not signed up then it puts stress on the medical profession to talk to mum and dad about their young man's organs helping others. That in itself is probably a burden that is not right to put on the medical profession. The medical profession has its own stresses at that time.

**Ms FORREST** - And they have probably been working on them really hard for some time.

**Mr SYPKES** - That is it exactly right, and then to ask, 'Can we have him?'. I think that is another level of expectation on the medicos and that is a tough one.

**Ms FORREST** - Are you suggesting that you almost need someone else who is trained and very informed about organ donation, the pros and cons and the whole bit, to come in at that time, rather than have the medical staff do it that have been providing that care? Someone separate could come in and take over the care of the parents or relatives who are going to have to make that decision, rather than the medical staff who are still busy dealing that situation in the ICU.

**Mr SYPKES** - Yes, but bear in mind that a lot of donations come from people that are ill. They are not all in emergency. There is a lot that come from people that have been in hospital for a month. I think there is a great opportunity for those patients, and the families of those people, to be spoken to while they are still alive. They are in hospital, knowing that it is terminal or knowing that they are not likely to survive. Sure there is the emergency stuff but I think they could probably be attacked separately.

**Ms FORREST** - Do you think the same person could do both jobs if there was a person responsible for that side of it?

**Mr SYPKES** - I think anything that is done under emergency is done under a lot of pressure for everybody and a lot of stress. If there is somebody available that can do that that then I think that is great. However, an emergency is just that - an emergency. You get a call that we need you now.

**Ms FORREST** - People who are employed in that capacity would be well aware of that. It is not like it happens every day.

**Mr SYPKES** - No.

**Ms FORREST** - How often would it happen in Tasmania?

**Mr SYPKES** - Very infrequently.

**Ms FORREST** - Unfortunately, but fortunately also that it is not very often. Doctors work like that all the time when they are on call.

**Mr SYPKES** - Sure do.

**CHAIR** - Any other questions.

**Mr SYPKES** - One more little thing. In Tasmania we have the two heads. We have a lung support group around Australia. It is generally called LungNet but here in Tassie we thought it appropriate that here we call it 'Two heads, Two Lungs'. So we have got a sense of humour still, we still live life to the full as much as we are able with two heads and two lungs.

**THE WITNESS WITHDREW.**

**Ms ELAINE FAY BOOTH** WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** - Thanks for coming along and being willing to give your evidence.

**Ms BOOTH** - I am just a recipient. I am happy to be alive; it is a wonderful gift a human being can give another human being. Before I had my transplant I had 11 per cent lung function and was very sick. It is just the most wonderful thing that can happen to a person, to breathe easy again.

**Ms FORREST** - How long did you have to wait?

**Ms BOOTH** - I was on the waiting list 18 months and in that time I attended the physio at the Royal under the care of Helen Cameron-Tucker. The support was just outstanding and I don't think without their help I would have got there.

**CHAIR** - How did your lung function reduce over that 18-month period?

**Ms BOOTH** - I gave up smoking in 1986 and I was diagnosed with bronchitis and asthma and of course I gave the cigarettes up straightaway, but over the years I just deteriorated and then my physician diagnosed me in about 1996 with emphysema. I also want you to know that my mother had emphysema and so did my sister, so my respiratory physician seems to think it could be in the genes in my case. I do not know. We probably suffer from weak chests or whatever.

**CHAIR** - What was your life like when you were diagnosed and how did your life decrease until you had the transplant?

**Ms BOOTH** - It decreased something incredible. I could not do anything. I could not walk from here to the other side of the table without having to lean on something to get my breath.

**CHAIR** - So that is about two metres.

**Ms BOOTH** - Absolutely. Showering was practically impossible. I just could not do things and I was so frustrated with trying to do them myself. I always loved doing things in the garden and stuff like that. It was just so frustrating. I can relate to the ones that are on the list and sympathise with them because I have been there and done that.

**Ms FORREST** - For you it was more a quality-of-life issue.

**Ms BOOTH** - Absolutely, not quantity but quality. I even said to the team when they came over that I did not mind if I got six months - just to be able to breathe easy again, to know what it is like to breathe without having to struggle to get your breath. It was an amazing experience.

**Ms FORREST** - So how long ago did you have the transplant?

**Ms BOOTH** - Five years in December this year.

**Ms FORREST** - You have not had any setbacks in that time.

**Ms BOOTH** - No, not really. I have had a few little hiccups but no rejection or anything like that, or infections. I have been very, very lucky. I got a good pair of lungs, I believe.

**Ms FORREST** - So you got a pair.

**Ms BOOTH** - I got one pair, yes - bilateral.

**CHAIR** - Are you on medication now.

**Ms BOOTH** - Yes, I am on rejection medication for the rest of my life. I cope with that very well and that is a matter of a balancing act in getting things to work properly. Your other organs of course suffer with all this medication you take, which is a natural thing and to be expected.

**CHAIR** - Before you had the transplant were you told what was to happen, the type of things you could expect?

**Ms BOOTH** - To a certain degree.

**CHAIR** - Do you believe that process was adequate or should it be improved? If it could be improved how could it be?

**Ms BOOTH** - They have improved it heaps by some of these TV shows you see now. I did not know as much then as I know now after having viewed some of these gift-of-life programs and things like that. I think it is tremendous because it needs to get out there amongst the people to let them know that organ donation is very much needed, especially in Tasmania. I know of desperately ill people on the lists. The cut-off point is 65. It cuts you off when you reach 65. If we had more donors and people were still well enough to have a transplant then they may extend the age from 65. They may have a weak heart or whatever the case may be and they may still be strong enough to have a transplant, if we had the donors.

**CHAIR** - How do you get more donors?

**Ms BOOTH** - Indeed, how do you get more donors? It is through Medicare at the moment. I put it on my driver's licence. The only other thing I can suggest is an enduring guardianship if someone registers to be a donor. They could be provided with an enduring guardianship form to fill in and then perhaps their wishes would be fulfilled and their family cannot interfere. That is one suggestion but it is so complicated.

**CHAIR** - Are you a donor now?

**Ms BOOTH** - I do not know. They said that I could not be because of the medication I take but if I am able to -

**CHAIR** - Were you previously?

**Ms BOOTH** – Yes, I was. It was on my driver's licence.

**CHAIR** - Were you told anything about it or you just had to tick the box?

**Ms BOOTH** – No, I just ticked the box. I thought that if you could help somebody else have a good quality of life you had to do it.

**Ms FORREST** - At the time did you think you might be a recipient? Did you know about your lung problems at that time when you ticked the box?

**Ms BOOTH** - Yes, I was sick at the time. When they first bought it in and I just kept it up even when I was sick. Even if they just take some tissues or arteries or something like that, you are still donating something. I do not know whether I can donate liver or whatever because of the medication. I have not really got to that question yet with my physician but that is a question I will ask him. If not, well so be it, but I would like to.

**CHAIR** - If you were in our position and looking into this what recommendations do you think we should come forward with.

**Ms BOOTH** - I suppose it is hard to convince the public to get their family members or themselves to register to be a donor. You just have to get it out there in the media. It is hard to say really.

**CHAIR** - There is 172 200-odd people who have signed the consent form to donate from Tasmania.

**Ms BOOTH** - Well that is good, but what happens if families intervene? That is what you have got to get across to all the members of families.

**Ms RATTRAY-WAGNER** - It is the discussion.

**Ms BOOTH** - It is the discussion aspect of it. My family know what my wishes are and I have discussed it with them and I am also filling in an enduring guardianship to the fact. That makes my wishes very clear to them.

**Ms RATTRAY-WAGNER** - It has suggested to us that there should be an organ donation coordinator for the State, or perhaps two part-time - one in the north and one in the south. That may assist in the education process and also in helping the medical staff, who are dealing with it at the coal face, to be more prepared and ready. What do you think about that?

**Ms BOOTH** - I think that is an excellent idea to have a coordinator in the north and south of Tasmania because they play a very vital part in the process. The organ transplant coordinators in Melbourne were just fantastic.

**Ms RATTRAY-WAGNER** - They are still a bit removed.

**Ms BOOTH** – You still have that gap there, very much so. It would be excellent if we had our own person that could get it out to the public. I think that is vital. I never thought I would need a transplant and my physician suggested that I have lung volume reduction

surgery but my lungs were too bad to have that so I had to have a transplant, which was very daunting to me at the beginning. I have no regrets whatsoever.

**Ms FORREST** - What do you do personally, Faye, in your own activities to try to promote it?

**Ms BOOTH** - I continue going up to physio every now and again at the Royal and I am still friends with a lot of people who are on the list. We have run that lung net that Rudi showed you - Two heads, Two lungs - in Kingston. I attend those meetings.

**CHAIR** - You are a contact point for them too.

**Ms BOOTH** - And I am a contact point, yes, for everybody.

**Ms FORREST** - What happens to the people that our outside that network.

**Ms BOOTH** - We are trying to get the people that our outside to get into the meetings to know that there is somebody there to support them if they need that support. Some of ladies and gentlemen that have come along to our meetings think it is wonderful to relate to tother people because some people do not know that we are there and there are others out there suffering from the same thing.

**Ms FORREST** - How long has that been going, the Two heads, Two lungs?

**Ms BOOTH** - Well we have just named it Two Heads, Two Lungs in the last, say, 12 months. We formed the group down in Kingston nearly two years ago, I guess.

**Ms FORREST** - Did you have a bit of a launch and a holistic campaign at the time?

**Ms BOOTH** - No we didn't. We just got together as a group. We just sent out some letters saying that if people with heart and lung problems wanted to join a group at the community centre in Kingston, they were welcome to come along, have a chat, cup of coffee, tea, whatever the case may be, and just talk about their problems. That is how it started and then of course Rudie came along and then we sort of got serious about it. Then we registered with Lungnet in Queensland and we are now trying to haul in some more people.

**Ms FORREST** - The fact you do not know who your recipient is or was and anything about their background, is that an issue for you? We heard evidence from someone saying that they thought if you are going to do an altruistic donation you would like to know something about the person at least.

**Ms BOOTH** - No. I didn't want to know. I wrote two letters to the family members to thank them. I was told by the coordinator that I was not allowed to know. All they told me was that it was a 45-year-old woman - nothing about her life or her circumstances, you know

**Ms FORREST** - Do you think that is an issue or do you think that is okay?

**Ms BOOTH** - Well it was not an issue with me but, yes, some people do want to meet the family members of the donor. I guess some of the donor families would like to meet the recipient so yes -

**Ms FORREST** - Do you think it is something like the adoption issue where originally there was no way of getting in touch with adoptive parents for example?

**Ms BOOTH** - Yes.

**Ms FORREST** - Now things have changed to allow that, if there is mutual agreement, those two people can meet. Is that something -

**Ms BOOTH** - I think it would be a good idea if they brought that in because then the people have a choice if they want to do it.

**Ms FORREST** - It is maybe something they do not want to do too soon after a person's death.

**Ms BOOTH** - Not too soon, no, but I mean a couple of years down the track. I wrote a letter while I was over in Melbourne to thank my donor family. Then just last year I wrote another one because without that gift I would not have been able to do what I was able to do.

**Ms FORREST** - How long did it take you from the operation to get to a point where you could have a reasonably active lifestyle?

**Ms BOOTH** - About six months I guess. I went over in the December and I was back in the April. Yes, I wanted to get stuck into things and do things, you know, I couldn't wait, but people still tended to say, 'Mum you can't do that' and so on. I said 'Listen, I can breathe now, I can do it'.

**Mrs RATTRAY-WAGNER** - It is called family protection.

**Ms BOOTH** - Absolutely it is, yes, that is right.

**CHAIR** - What type of things are you doing now, Faye, that you could not do beforehand?

**Ms BOOTH** - Mowing the lawns. Just doing everything I could not possibly do before, you know - vacuuming and walking.

**Ms FORREST** - Showering?

**Ms BOOTH** - Showering, oh yes, showering. All the little things you can imagine you can't do when you are very sick on oxygen and in a wheelchair.

**CHAIR** - You were that bad, were you? On oxygen in a wheelchair?

**Ms BOOTH** - Yes. I went up to a friend who had had a heart transplant. He was still going to physio at the Royal and when I went up in the wheelchair he said, 'Faye, it won't be long. You will be over there, it won't be long' and he was right. I was over there in the

December. I just got to the stage where I just couldn't breathe without the oxygen and I couldn't get around without a wheelchair. Now it is just so wonderful. It brings tears to my eyes really when I watch some of those medical stories, you know, and I think -

**Mrs RATTRAY-WAGNER** - I can tell you it has been a bit heart-wrenching here today too.

**Ms BOOTH** - I'll bet it has, yes.

**Mrs RATTRAY-WAGNER** - A couple of times I think some of us would have liked to have died for those tissues.

**Ms BOOTH** - Yes, yes, that is right.

**Mrs RATTRAY-WAGNER**- Listening to people's stories, especially from the mum whose son had been a donor.

**Ms BOOTH** - Yes, it is good to get every side, isn't it, to know how they feel. That is about it for me.

**CHAIR** - Thank you very much. That was helpful. I know Rudie, when I was speaking with him, said that there were a couple of people who he thought would be helpful in letting us know how you feel now.

**Ms BOOTH** - Yes. It is good to hear the other side of it, from the recipients, yes.

**CHAIR** - To let you in on what is going on: we come back with recommendations; we write a report; there is a Commonwealth inquiry going on at the moment. They are coming back with their results, I understand, in December so rather than going in divergent ways it is best to wait to see what happens in December and see if we can dovetail in with them.

**Ms BOOTH** - Right, okay, great.

**CHAIR** - Thank you for your evidence and thank for coming along.

**Ms BOOTH** - My pleasure.

**Mrs RATTRAY-WAGNER** - Spread the word and fill out forms. We will.

**Ms BOOTH** - I will. Yes, well, they do not give you enough information on those though I don't think. I went to Medicare and they did not know of transplanted people. They don't know whether we can donate.

**Ms FORREST** - If you had a coordinator in the State and there was a brief on all those matters and a point of contact that may be of use?

**Ms BOOTH** - Yes, absolutely.

**Ms FORREST** - You would think your corneas at least would be all right, wouldn't they?

**Ms BOOTH** - Well, that is what I thought, my eyes, yes, the corneas would be fine or even if my heart valves or whatever are in good nick, they are not all cluttered up with gunk or whatever.

**Mrs RATTRAY-WAGNER** - Or skin tissue.

**Ms BOOTH** - Or skin tissue.

**Mrs RATTRAY-WAGNER** - I am sure you have got lots of good bits, Faye.

**Ms BOOTH** - I am sure I have, yes.

**Mrs RATTRAY-WAGNER** - Probably a lot better than some of us along here.

**Ms FORREST** - You speak for yourself.

**CHAIR** - Thanks Faye, thank you very much.

**THE WITNESS WITHDREW.**