

**THE LEGISLATIVE COUNCIL SELECT COMMITTEE ON ORGAN DONATION
MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART ON
WEDNESDAY 3 OCTOBER 2007.**

Mr AARON MACKRILL WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Wilkinson) - Aaron, thanks for coming along this morning. Please start your presentation and then we will ask some questions.

Mr MACKRILL - I am here today with quite a few hats on. I am an organ recipient; I had a double-lung transplant in December 2000 for cystic fibrosis. I am also the vice-president of Cystic Fibrosis Tasmania and in that position I have a role in helping people with organ transplants. More recently, I am on the executive committee of the Tasmanian branch of Transplant Australia. I have been asked from all areas to come and give a presentation to you about my experiences and what I think needs to change.

You guys probably know all the statistics. Organ donation rates in Tasmania are abysmal yet we do receive quite a lot of organs from the mainland. I think a lot of the education that has been done in the past has not met the needs of the people who need to get that information. I am also a registered nurse so I am in the hospitals lot. I am on a surgical ward so I don't encounter death a lot but I know that, when there is a death where I work, organ donation is not even mentioned. I am in a private hospital but I think they need to have a team of some description so that, when there is a death, they can talk to the family. I think there are so many eligible people who are passing away who would quite happily donate their organs but they are not being assessed and asked. I know there is a very small window of opportunity for organ donation to occur.

The thing that is being thrown around at the moment is this opt-out clause that is done in France at the moment. I personally think that is a great idea, but by the same token before it is brought in the public still needs to be educated on the whole process of organ donation and the fact that it is done surgically, just as if the person were alive. It is not a bunch of students hacking the organs out and desecrating the body - and a lot of people still think that. An education campaign could be put out to say, 'We want to bring in this opt-out clause', because it is an inconvenience for people to have to register for organ donation and things like that. If you bring in the opt-out clause then people, if they feel really strongly about it, will go ahead with it. If you give them the education and then bring in the clause then people will be able to make an informed decision on whether they really do want to opt-out or stay in and donate their organs. Instead of opting out totally they could say, 'I don't want to donate my eyes', and some sort of database could be set up.

There are a few issues, especially for Tasmanians, in the fact that all organ transplants have to travel to the mainland. That is probably why the donation rate in Tasmania might be a bit lower, because we don't do the operations here in Tasmania. Possibly we do not get as much publicity as some of the mainland hospitals. Most people who live

around the Alfred Hospital know that they do transplants there, so it is probably in the back of their minds. People who have never been to the mainland or who don't watch shows on TV such as *The Gift* probably aren't even aware of it. You have to be able to reach those sorts of people as well.

It may be worthwhile visiting schools and starting to educate the kids as well. Schools do sex education so maybe they could do some sort of organ-donation education. You would probably have to get parents' consent because it is a very touchy area. You would probably aim it at high schools and colleges. I think the key thing is education, to educate the public and give them the facts and tell them that everything is fine.

I know a lot of people who have had transplants who are always happy to give talks and presentations and share life experiences. My life has changed dramatically. I finished my Bachelor of Nursing degree, got married and we are in the process of doing IVF to have kids. I was told that I wouldn't see my twenty-first birthday without a transplant. It is such a life-changing event.

CHAIR - How old are you now?

Mr MACKRILL - I am 27. There is so much positive that can come out of it. One person can save seven lives with their organ donation, especially with livers, which can be divided to more than one donor. It is a fantastic thing.

CHAIR - Is that right with livers? I heard that you don't need the whole liver to be transplanted, just part.

Mr MACKRILL - The liver is an amazing thing. Like kidneys, you can be a live donor. With a live donor they leave about 60 per cent of the liver and put it into the donor and within two to three weeks both livers are fully regenerated to full size again. It is just incredible and science does not know how it does it. It is the only organ in the body that does it. Kidneys and livers are always a great thing because there are live donors available as well.

Mrs RATTRAY-WAGNER - Does much of that happen, Aaron? I have heard a lot of about live kidney donors but not much about livers.

Mr MACKRILL - Not a heck of a lot, I don't think, because it is more major operation than for kidneys. *The Gift*, which is show on TDT down here, is about organ donation. They did a live-donor liver transplant - a guy donated his liver to his cousin - and the way the livers regenerate was incredible.

CHAIR - Within how long?

Mr MACKRILL - Two to three weeks the ultrasound showed that both livers had fully regenerated. It is a pity all the organs don't do that.

CHAIR - So education is obviously big on the agenda?

Mr MACKRILL - Yes.

CHAIR - If there is a death, organ donation in the hospital that you work in isn't spoken about at all?

Mr MACKRILL - Not to my knowledge, no. I have been a nurse for about four years now and I have probably seen a dozen deaths in my time. In all the deaths I have been involved with nothing has ever been broached in regard to organ donation. Admittedly not every single one would have been eligible but by the same token there were probably a couple of circumstances where it would have been appropriate and we didn't have the resources to follow it up. I don't know whether that is something that can be looked at; the private sector is a very difficult area of the health system to get that sort of thing initiated. If it is set up in the public sector, the private sector usually follows. It would probably be a worthwhile thing. I know there is an organisation called LifeGift and they would probably be a good resource for getting something like that set up.

Ms FORREST - Aaron, you work on the surgical ward?

Mr MACKRILL - Yes.

Ms FORREST - At the hospital you work at is there an ICU?

Mr MACKRILL - Not a ventilated ICU. I am at the Hobart Private and our coronary care unit has a co-location agreement with the Royal. We have put in a licence to get ventilated beds but there are private patients in ICU and vice versa, so it is a co-location.

Ms FORREST - Because the deaths occurred in the surgical ward, is that a factor that made it less likely to be considered? If that patient had been transferred to ICU because of their condition and subsequently died in ICU, do you think it would have been discussed then? Or is it still not a thing that is discussed?

Mr MACKRILL - I did a very short stint in ICU and with the deaths that occurred nothing was instigated. I am talking about four years ago. Even on a surgical ward corneal transplants can occur because they don't have to come from a ventilated patient because blood doesn't flow through the cornea. Anybody can donate their corneas, even if they have cancer or something like that. They are the one thing that every Joe Blow can donate, unless they have eye disease. I know it is only something simple but the waiting list for cornea transplants I think would be fairly high. I think every opportunity should be taken to get organs to give people quality of life. I know there are a lot of religious aspects to organ donation, but the soul lives on; the body is really just the carrier for the soul as far as I am concerned. Once you have used the shell you may as well make use of it and give somebody else a better quality of life.

Ms FORREST - Do you think corneal transplant doesn't get perhaps quite the level of attention because it is not life saving - it is quality of life? If it is your kidneys, liver or lungs, they are certainly life saving.

Mr MACKRILL - Definitely, yes. I represented Tasmania at the Australian Transplant Games last year and there was a bit of a stigma that people who had had corneal transplants, and even bone marrow transplants, are seen as not as important as the organ graft transplants. With bone marrow transplants they get rid of the immune system but once they are back on their feet they do not have to take any medication and they are just

like a normal person again, whereas people with organ donation are on medication for the rest of their life and it affects them every day. It is the same with corneal transplants; to my knowledge they do not need medication and I think that is why there is a bit of a divide in the ranks.

CHAIR - What did you represent Tasmania in?

Mr MACKRILL - What didn't I represent them in. I competed in athletics - I did the sprinting races and the field events - played squash, tennis, ten-pin bowling, eight ball, golf and came back with 10 medals.

CHAIR - It sounds like you were the team.

Laughter.

Mr MACKRILL - There were only five of us.

CHAIR - Obviously with the cystic fibrosis you have never been able to compete in those things before; is that true?

Mr MACKRILL - As a child I was all right. In primary school I was in little athletics and was actually a really good runner and then, as my lung disease progressed and I got into high school and college, I spent more time in hospitals and what not. I got to the point where, just before my transplant, I was on a home oxygen-concentration machine and could not walk to the letterbox without gasping for breath. It was a fantastic achievement to get back, and it was so much fun too.

Mr HARRISS - Could you give us a bit of an idea of the process, how long you had to wait and whether there was some despair along the way that you might not have got access to the organ donation?

Mr MACKRILL - Initially, I would have been 18 when the doctor basically said, 'Okay, if you don't have a transplant you're not going to see your twenty-first birthday'. People with chronic illnesses, as you probably know, do grow up a bit quicker than most, so I thought, 'I have a shit life, to be honest, and I don't want to have to go through the whole transplant process' because I did not really know much about it anyway, so I initially refused. Then when I was 19 a good friend of mine with cystic fibrosis died and he had been on the waiting list for two weeks. I saw his parents and I just could not do that to my parents and so I said, 'Right, I'll go ahead with it'.

I contacted the doctor and I had to go to Melbourne for a week to do all the assessments. I was an in-patient in the hospital for a week and had basically every test known to man, which was pretty hard, especially on my parents because they both worked full-time. One of them had to take a week off work and come and stay with me. The PTS subsidised it a little bit but it did not cover the full costs. Interestingly enough, seven years ago they paid \$30 a night and now it is only \$33, which I think is just abysmal.

I got assessed and after all the tests were done they put me on to the waiting list. It was twelve-and-a-half months of waiting, which included seven false alarms. Luckily I had not got to Melbourne before they rang up and said, 'No, sorry'. Each time you just think,

'I don't think it's ever going to happen', because the first time it goes off your adrenalin starts running but towards the end of it I was getting pretty despondent. Twelve-and-a-half months when you are basically living an interim death is just pretty bad. It was really hard on my family and I had to quit school and everything because I just could not function. I pretty much just lived in my bedroom at home and when I finally got the call it was just amazing. I went over on the air ambulance and four hours later I was under the knife and I woke up 10 hours later with the transplant.

It was really, really hard on my parents again because of full-time work. My dad got really sick because he was over there for the first four weeks and it was not an easy thing to go through. I have talked to numerous cystic fibrosis people who are thinking of lung transplantation. One thing that has always stuck in my mind is when I saw the counsellor from the Alfred, because you have to have a psychiatric assessment just to make sure that you can cope with the fact that you know you have somebody else's lungs inside you. That is a massive thing to deal with and even now I think somebody died to give me life. One of the things they said to me is that a transplant of any description is not a cure: you are just exchanging one set of problems for another. Even though I have had a transplant and my quality of life is excellent, I still have to take 50 pills a day. I still have to make sure that I do not get infections because I am immuno-suppressed. I have to stay out of the sunlight because the medication can give me skin cancer. So you have to weigh up the positives with the negatives. The fact that I can walk upstairs is proof that it is great and I have not really had any problems now.

I lived in Melbourne for four months. The usual time is three months but unfortunately a week before I was due to come home they diagnosed me with diabetes, which is a common cystic fibrosis-related disorder, so I was over there for another month while they stabilised my sugars. Then I came home and went back to uni, finished my degree, met a chick and married her.

CHAIR - And away you go.

Mr MACKRILL - Yes.

Ms FORREST - With your parents, you said it was difficult for them for a number of reasons, so what sort of support did they get? As a mother, I would probably need a bit of help with accepting that my daughter was going to have someone else's lungs in her body.

Mr MACKRILL - In my experience it was very patient-focused. My parents were divorced but they get on fine so that was not an issue, but my step-parents were causing problems and all that sort of stuff as well. The social worker did talk to my mum and dad a little bit but it was very much patient-focused, with mum and dad always just in the background. I was a 20-year-old adult as well, not dependent on my parents as much, but I do think that at the time my parents probably did need a little bit more support. I have little brothers and they left them with my step-parents. They came over to stay with me for a month so they were having problems back home themselves. As a totally unrelated thing, my mum was diagnosed with breast cancer while I was having my transplant, so it was just a horrible time.

There probably could have been a little bit more support for them but just the fact that I was doing well helped them to cope, and I talked it through with them. The nursing staff and the doctors were fantastic as well. They are really supportive.

CHAIR - Which hospital was it?

Mr MACKRILL - The Alfred.

Mr HARRISS - Aaron, in relationship to parental support and if I put myself in that position, if you were happy I would be delighted - 'My kid has made it and there is a chance'. Is that the sort of relationship and is that the way they feel?

Mr MACKRILL - Yes.

Mr HARRISS - They did not particularly need any support other than to see you doing all right?

Mr MACKRILL - Yes. They were supporting me the whole way through the assessment period. It was never an issue of, 'We don't want you to do this' or whatever. Over my whole life my parents have been very supportive of me in any decision that I have made. They are always there to guide me if I needed it but once I had made the decision they had a contingency plan ready for when I went to Melbourne for the transplant. Throughout the whole experience they were always there to support me in everything and it was really good.

Ms FORREST - Do you have any siblings who are sufferers of CF?

Mr MACKRILL - No. I have four half-brothers. CF is a recessive gene and my step-parents, to my knowledge, don't have the gene. It is highly possible that one, if not all, of my half-brothers are carriers, but none of them has the disease.

Ms FORREST - On the issue of informed consent, you said you supported consideration of the opt-out process. We have had some people suggest that it is very difficult to get informed consent with an opt-out because people don't always respond. If the requirement is to opt out rather than opt in, those people who choose to opt out have to register to say they are opting out, so information about those people could be kept on some government-managed register. Do you think that is an issue for people who do not like to have their details recorded with the government, whereas it is easier to say, 'I will opt in because I'm happy to have my details recorded'?

Mr MACKRILL - Yes. With the way the organ donation register works at the moment - registering with Medicare and getting a card - that is why we have the privacy act. All the details are not going to be made available to anyone. The human race is very lazy and if we have to do something that is not important to our particular lives then I don't think we do it. That is why there are probably thousands of people who would be happy to donate their organs but they just haven't registered. If there is an opt-out clause there are going to be the people who don't want to register, but when they are sick or if they are in a car accident or something, they are not going to be able to say, 'I don't want to have it done now'. There are issues with the current system now and there would be issues with a new opt-out system if it was implemented. I think the sort of population we

are talking about that would be worried about having their details with a government agency would be very minor. Every single person is registered with Centrelink at some stage anyway, so it is not really any different as far as I am concerned. They are a government agency. Everyone has a Medicare card, so Medicare already has their details. It could be just a little tick box saying, 'I don't want my organs donated', on their personal profile at Medicare. I don't think it would be that much of an issue.

Ms FORREST - I think there could be a problem with the opt-out clause when, say, a person comes into ICU with a head injury and is unable to verbalise their wishes; they haven't opted out, so they are in, but what if the family is not happy to proceed with organ donation? Do you think a doctor would be willing and competent to operate on the person once they are declared brain dead and the decision is made? Or do you think it is still going to come back, even in an opt-out situation, to consent of the family?

Mr MACKRILL - You probably still need to have the consent of the family. In the whole organ donation process families are very important. At the moment with the current system we push for people to register and then to discuss what they want to do with their family. When it comes to the crunch they are the ones who make the decision. It doesn't matter what you personally want; if you haven't discussed your wishes with the family, at the moment they can override any decision that you may or may not want. Definitely you should have next of kin or family to make sure about a situation in the ICU if this person hasn't opted out and they want to. We cannot be too brutish with the procedure. If the family is absolutely adamant that they don't want the organs harvested, that is fine. You have to be ethical about it. You can't just rush in and take the organs against the family's wishes.

Ms FORREST - Do you think you could achieve the same end with an opt-in process, with much more education and promotion such as an annual event that really promotes it, a whole big campaign that was a regular event and not just a one-off? Do you think you could achieve the same sort of end with the opt-in system rather than the opt-out?

Mr MACKRILL - Every year we do have Organ Donation Awareness Week, and there are lots of things that happen every single year in regard to that. There are other things that happen such as the Transplant Games. If you look at the statistics, every time there is an Organ Donation Awareness Week or the Transplant Games or whatever, organ donation registry rates rise in that particular period. There probably could be a little bit more done nationally, especially in Tasmania, during these particular times.

Ms FORREST - I was not aware that it actually went on. We had a discussion with a couple of other witnesses and they did not seem to be aware. I said a day but you are saying it is a week.

Mr MACKRILL - It is a week.

CHAIR - Is it the same week each year?

Mr MACKRILL - I cannot even remember what month it is in because I have only just found out recently when I joined the Transplant Australia Committee. That just goes to show that Tasmania obviously is not involved in the celebrations.

CHAIR - If we want to get that information, what do we do? Could you get it for us?

Mr MACKRILL - Yes. There is also the transplant web site, transplant.org.au, but I definitely would be able to get some more information to you.

CHAIR - This education thing seems to be one of the major issues, but I was not aware of Organ Donation Week.

Ms FORREST - And other witnesses have not been either.

CHAIR - It would be good to have some information about that to find out why nobody had been aware of it down here.

Mr MACKRILL - I thought that there would be something like that because when I went to the Transplant Games there was a lot of educational stuff for awareness and things like that. Every other charity has an awareness day or week. I just cannot remember the exact time but I will let you know. It would be a really good opportunity during that time to actually push some -

Mrs RATTRAY-WAGNER - Build the awareness within the wider community.

Mr MACKRILL - Yes. That is the thing with any charitable cause - awareness is the key. I have been involved with cystic fibrosis, which is a genetic disease, for five years now and there are still people in the health profession who, when you say 'cystic fibrosis', say, 'How did you get that?' or 'How did you catch it?'. Also, there are so many charities now. When you are up against things like cancer and heart disease many little charities do get missed, which is understandable.

Ms FORREST - I remember '65 Roses', which raised awareness at that time.

Mr MACKRILL - Education is the main focus at the moment, just getting people aware of the process and so on. Perhaps if people are educated and if all of a sudden the opt-in thing does take off and it works well then we probably would not need the opt-out option. Get the education done first and see if donation picks up, especially here in Tasmania, and get some sort of process in place whereby if people do want to donate then there is a team that can take the organs and so on.

Mrs RATTRAY-WAGNER - It has been suggested that a coordinator for Tasmania, whether it be one in the north and one in the south or just one overall, would be a big advantage to work with health professionals and the community.

Mr MACKRILL - Yes. I reckon a statewide coordinator is needed. You would not get enough cases for a north and a south -

Mrs RATTRAY-WAGNER - A part-time split?

Mr MACKRILL - That is just promoting parochialism, I think.

Mrs RATTRAY-WAGNER - Do you burn out one person, though? Perhaps one dedicated person could do it.

CHAIR - Did you learn about organ donation during your nursing degree? Was it discussed at all?

Mr MACKRILL - No, it was not part of the course at all.

CHAIR - That could be part of the course, which would be worthwhile. The medical profession have not been taught about it either and are just starting to speak about it.

Mr MACKRILL - It would be a good idea.

CHAIR - Thank you very much for coming along.

THE WITNESS WITHDREW.