

**THE LEGISLATIVE COUNCIL SELECT COMMITTEE ON ORGAN DONATION  
MET IN THE PLAZA ROOM, PARLIAMENT HOUSE, ADELAIDE ON 27  
NOVEMBER 2007.**

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DISCUSSION WITH Mrs MARCIA COLEMAN, NATIONAL ORGAN DONATION COLLABORATIVE, Mr TERRY SLATER, AUSTRALIANS DONATE, Dr GERRY O'CALLAGHAN, CLINICAL LEADER OF THE NATIONAL COLLABORATIVE, AND Ms KATHY HEE, SOUTH AUSTRALIAN ORGAN DONATION AGENCY.

**CHAIR** (Mr Wilkinson) - We understand there is the National Collaborative and I know you are from it and thank you for assisting. What we do not want to do is to cut in across that at all. We want to, if we can, tie in with that. We understand there is a draft report coming down in December and that would then go to the minister. We would get that at some stage, I do not know when but that will be question to you, and then hopefully we will come down with our report soon after the National Collaborative's.

**Mrs COLEMAN** - Thank you and the committee for the invitation to appear before you. It is kind of you to allow us the opportunity to reinforce, embellish and add to what we have already presented to you. With me today I have Dr Gerry O'Callaghan and, as you know, Gerry is chairman of the planning group for the National Collaborative. Kathy Hee is Manager of the South Australian Organ Donation Agency and is also Chair of the State Managers Group. Terry Slater is the Chief Executive Officer of Australians Donate. Our corporate consultant sits on the side there.

We appreciate the opportunity to make a submission to your inquiry. I do not intend to go over that submission in these opening remarks but we do stand ready to answer any questions that you might have on it. I want to say that there is a challenge for all stakeholders in the organ and tissue donation sector. It is primarily to engage Australians in the importance of organ and tissue donation and to become positive towards organ and tissue donation in the circumstances that might prevail when they die and that is the unique circumstance of dying basically in an intensive care unit. Having made the positive decision, people must be encouraged to have an important conversation with their loved ones or a family chat, whatever people want to call it, so that family members are aware of their wishes. To facilitate that we should provide encouragement as well as a simple means for them to register their intent on an effective national organ donor register.

Secondly, our hospitals have a focus on ensuring to the extent practicable that every potential organ donor is recognised and that if that tragic circumstance arises, that donation is facilitated, encouraged and contributes to the best end-of-life care that the potential donor might experience and gives vent to their wishes at that time.

We note that there are fewer shootings because of strict gun laws. Drink-driving laws have had an impact on the potential numbers of people who die in circumstances where donation might become possible. We note that ABS brakes, airbags, electronic vehicle stability controls - I do not know that terminology so I really have to read carefully -

*Laughter.*

**CHAIR** - You'll be going down to Phillip Island it seems, Marcia, over the weekend. I think that is the last of the car racing.

**Mrs COLEMAN** - Reductions in cardiovascular and ischemic stroke events because of an improved lifestyle also have an impact and the availability of new therapeutic agents and the better management of cerebral events. AD therefore has put its efforts into two main areas and I am pleased to have Gerry O'Callaghan and Kathy Hee here, who are experts in the organ and tissue donation sector. Gerry is an intensive care specialist and Kathy, as I have mentioned, has a role as head of the South Australian agency. They have contributed greatly to the national collaborative.

Lastly, I want to mention that Australians Donate funding ceases on 31 March 2008 under the present arrangements. It is 100 per cent funded by Australian State and Territory governments on a cost-shared basis and 50:50 is the arrangement at present. At present governments are looking at how they wish to take forward the work of Australians Donate into the future and in what form. The model they have presently under consideration is one which takes most of this work back into the Government, quite likely the Federal Government in the first instance, under the auspices of a cognate committee with representatives of all governments, clinicians and other stakeholders.

With that, I am pleased to respond to any questions that you might have. I have a small body of information here which I could pass to you for distribution at some stage if you would like it.

**CHAIR** - Yes, please. Thank you.

In relation to Tasmania, it would seem from the evidence that we have had to date the intention is good, that is that there are about 150 000 Tasmanians that have ticked their licence as being willing to donate. In relation to the form that you get from Medicare, which is the form that is used in Tasmania, it is around about 20 000, so there is around about 170 000-odd, give or take because we do not know whether there is any doubling up with the licence and the forms that were filled in, but there would seem to be a fairly good uptake of people giving that intention.

What we have to do is push the 150 000 licence-tickers into the requisite form which you obtain at Medicare. That, to us, seems a bit of a problem. How do you think we can fix that?

**Mrs COLEMAN** - Can I give you an example of what occurred in February this year in Hobart when I launched the Organ Donor Awareness Week at a secondary college. There were about 500 students there and we had trialled an SMS message that a person could SMS to a certain number. The Hobart Call Centre, which is very efficiently run down there, would SMS back and ask someone for their full name, the name of their street and the street number and then a further SMS would come back when that was responded to and a registration pack would be on the way to that individual. It was quite a unique experiment for us because at 11.42 on the night that I launched Organ Donor Awareness Week at that college the call centre was inundated with responses through the

SMS message. We believe that was because a student from the secondary college had died as a result of an asthma attack and her organs had been donated. That resonated with the kids in the college and there was that very good response.

I mention that because it is a fairly unique example of how interest in registering can be generated. The trial did not run for a long time but it was successful for the period.

One of the most important things is for a family to be aware that a person has indicated a wish to be an organ donor, whether it be by registration or by discussing it with the family. Where a family is aware that a person has expressed a wish, in the vast majority of cases that wish is upheld by the family. I think that Kathy and Gerry might want to comment on that indication by a family to honour the wishes.

**CHAIR** - We were told yesterday and previously that South Australia is doing it extremely well.

**Ms HEE** - We have been doing well since 1996 when the agency was set up but that is for a whole range of factors and not simply to do with the register. The register is only useful to us if people access it at the time - if the intensivist or the hospital accesses that register to find out what the wishes are. Unfortunately that does not always happen. There is a problem with the registration. Where we are referred a donor from an intensive care unit my coordinators immediately access that register but by then the talk with the family is usually over. But we do know that if they know the wishes of the person, whether it be via the AODR or by talking in the family, about 98 per cent of families will say yes. There are very few instances where the family would override a person's wishes. Where they do not know the wishes then probably about 50 per cent of the time they will say no and that is because they are unsure of the person's wishes, not because they are necessarily against organ donation.

**CHAIR** - Is that in South Australia or is that Australia-wide?

**Ms HEE** - I think that is pretty much Australia-wide really; it is not just the South Australian experience.

**CHAIR** - So you are saying even though you come into these committees with ideas and those ideas are either firmed up or alternatively get blown out the window, the registration does not always work because the hospitals do not often go into that registration or there is something wrong with it prior to or at the time and therefore the talk with the family is the biggest thing because obviously that is the consent that you need.

**Ms HEE** - I think you can fix that problem.

**CHAIR** - How is that?

**Ms HEE** - You can legislate or you can do whatever you want to do to ensure that people access the register before they speak to the family, if you want to go down that pathway. That is one way you could fix it.

**Dr O'CALLAGHAN** - There is very little international evidence or even local evidence that accessing the register is correlated with organ donation rates, so although it is sensible if we are going to have a register to try to do it as well as we can, in terms of the focus of improving performance our registers themselves have not been shown to be particularly productive.

We know from research done in Australia that about 50 per cent of potential organ donors die in emergency departments and are unrealised or unrecognised and then a subsequent 50 per cent within intensive care units. There is probably a smaller number of potential organ donors who die in other parts of the hospital but really I think in terms of improving performance, there would be an enormous amount of effort required for very little return for pursuing those opportunities.

The point that Kathy makes is in terms of respecting pre-existing wishes of an individual who dies and that is ultimately what this process is about. It is an end-of-life care issue and it is about exploring those issues with families and making sure that the wishes of someone who has died are respected, where they are known, and where they are not known, asking family individuals, advocates, what they think their wishes would have been if they were able to tell you.

**CHAIR** - Are you saying, Gerry, that it would seem that normally when the question is asked, the doctors or the intensivists or the nurses are not aware of the register so therefore they are asking without the knowledge of consent or otherwise?

**Dr O'CALLAGHAN** - That is often true but the issue was more that the clinical presentation of such individuals is not recognised or responded to in terms of its relevance to organ donation. So often somebody might present as critical in an emergency department and have a very poor prognosis and they may have palliative care initiated in the emergency department and die there and the organ donation issue is never raised. If it is never raised then, of course, there is never any capacity to consult the registry and then that information never comes to light. So it is really more about having processes and individuals in your hospitals who make that the focus of their activity, that at some point in the context of end-of-life care there are discussions about the issue of organ donation and there is an appropriate conversation about that by somebody who is sufficiently informed and experienced to be able to contribute to the clinical care of that individual and the outcome of that conversation is then selected.

I completely support Kathy's point, which is that once you get involved in that conversation then it is appropriate to consult with the information that might be on that that would inform the family's decision. But that in itself is not the problem. In some hospitals in Australia we have very good consent rates; other places consult the AODR all the time and don't turn that into improved performance.

**CHAIR** - What's the process you have in place that makes your system work?

**Dr O'CALLAGHAN** - To call it a system is perhaps to not understand the organic nature of it all. It really is about individuals and relationships, and relationships between individuals within a hospital and between organisations such as the State-based organ donation agency. There is a very strong presence in the hospitals of organ donor coordinators, depending on the size of the hospital, spending a day or two a week liaising

with clinical staff, organising education, and they are very much part of the team. They have been involved for a long time in auditing performance assessment, so they do death audits, caseload reviews and then they follow up with individual support and discuss issues as to why a person did or did not become an organ donor and whether or not there were any process issues that might need to be addressed.

**CHAIR** - Who does that?

**Ms HEE** - The way we're set up in South Australia is that we have organ donor coordinators attached to the agency. We also have what we call 'medical donor coordinators' - and Gerry is one of those people; he is at Flinders. In all of the major hospitals that have intensive care units we have a designated medical donor coordinator and we have an organ donor coordinator who works for the agency. In most instances in the big hospitals those organ donor coordinators in Flinders and the Royal Adelaide work at least three days a week in that hospital - Monday, Tuesday and Friday. They have an office in or just outside the intensive care unit and they are seen as part of the hospital team. The medical donor coordinators and the organ donor coordinators work very closely together on all sorts of things. The organ donor coordinators attend the M&M - morbidity and mortality - meetings, which are standard in all intensive care units. If there is somebody in that intensive care unit who should have been a donor but who wasn't, questions are asked at that meeting. Because the coordinator is seen, is there, is available, is seen as part of that team and is integral to that team, I think that is really why it works.

They know where the potential donors are. Because they are seen and known in the hospital, whether or not there is an actual referral to us, they will be told by the staff that there is a potential donor in the hospital, in the ward. They are not at the end of the bed doing things like that, but because they are told they just keep an eye on what is going on and there is much more likelihood that that donor will be converted, if you like.

You need to fix your intensive care units as an initial thing. I agree with Gerry, it is about identifying potential donors in the first instance. If you don't identify who may be a donor, you can't end up converting that to an actual donor, so those patients get lost.

**CHAIR** - Say I come in with a life-threatening illness, it appears that I am not going to make it, I am a potential donor and I want to donate, how would you know that? Would one of the coordinators come in and see me?

**Ms HEE** - If you're at the point where the doctors are saying, 'There's a person here we think they've coned' -

**CHAIR** - Did you say 'coned'?

**Ms HEE** - Yes, it is in brain death, when the brain swells. It goes into the top of your spinal cord - that mechanism is called 'coning'. Once the blood supply is cut off then the brain becomes dead. So in that situation the donor coordinators there would ring up the AODR and find out if that person is a potential donor, but it does not happen until then. Many times it happens well and truly after the event.

**CHAIR** - But that is the first step. That person may have expressed their interest and signed the register. But as you say, that is not the be-all and end-all. That person may still wish to donate.

**Ms HEE** - The family can still override the new consent register too.

**CHAIR** - But what are we going to do with that situation where they are not on the register and you believe they might be a potential donor? What happens there?

**Dr O'CALLAGHAN** - I am not quite sure if the situation is entirely clear. An individual is usually not in a position to indicate their preference. So that either has been predetermined and is prerecorded or has to be explored in discussion with the family. Organ donation is usually only relevant in the context of deaths that are sudden, unpredictable and an event that renders an individual incapable of communication. The usual happening is that they may die in a very short term and they are physiologically unstable. One of the most important tools that doctors have in terms of prognosis with respect to an individual presentation is response to treatment, and that is one of the most important things that allows us then to advise families what our expectations are and what they should prepare themselves for.

So organ donation can only really occur effectively in the context of addressing a person's clinical presentation properly and I think it is, in a general sense, often reflective of the journey that that patient and family have had in the public hospital system so that their clinical problems can be appropriately addressed. Part of that is palliative care and part of palliative care is discussing the different end-of-life options and relevant issues.

When someone presents to the emergency department it is not as important whether or not it is under their driver's licence or AODR, as the fact that they are treated well and that at some point an appropriately senior doctor who is experienced has a discussion with them about end-of-life care and that is not left to inexperienced or inappropriately trained people. That is often the case across the country, due to work pressures. So it really has to be imbedded in the culture of an organisation. What happens in South Australia is as a consequence of the work of a generation of doctors in different public hospitals. We are fortunate that Kathy has been part of that work for the last two decades. We are fortunate to have the results of their hard work. But it is very much in the culture of the organisations in the emergency department to have the capacity to refer those cases to the intensive care unit for physiological support and for appropriate care while we sort that out. There are a whole range of other people involved in the team - volunteers, bedside nurses, social workers - and they are referred sometimes at the family's request and sometimes at the treating doctor's instigation to the organ donation agency and then some people come and talk to the family.

In South Australia specifically what we do there is a bit different, as often we do consent together with the organ donor coordinator and sometimes the doctors will do it and sometimes they will do it. Often we do it together. By and large, I think a certain amount of our success in this is the fact that we have a public hospital system whereby those individuals are well received and their families and the treatment is well received within the intensive care units and we do not seek to get involved in palliative care early in the emergency departments. That is not just because of the issue of organ donation;

that is just because I think there is a general sense that in a busy emergency department that is not really an appropriate place for many people to die.

**CHAIR** - Sure. It is the culture more than anything else then. Am I right in saying that? The culture that has grown up in the hospital more than anything?

**Ms HEE** - The culture is the result of a lot of hard work. I think Gerry has hit on it. It is about senior, appropriately trained people having identified people and doing that request. We notice that many times when junior doctors do the request they get a no because they are not experienced in that request, so having somebody appropriately trained and appropriately senior is a very important part of the request.

**CHAIR** - Why is that? Is it because of the trust that the family has in that person and the knowledge and expertise that they realise that person has?

**Ms HEE** - I think that is part of it and I think the other part of it is if you get junior doctors doing it they often do not know very much about organ donation. Organ donation is only a very small part of what occurs in an ICU and a very small part of the work. Even in large hospitals a junior doctor may not see an organ donation in his or her term of duty in that environment. Or if they do, they might see just one and that means that they are inexperienced, whereas people like Gerry have done the request over and over again so he is going to be better at it.

**CHAIR** - But these younger people have to start because they might be the Gerrys of years to come.

**Dr O'CALLAGAN** - That is right. Let me give an example. It is a Sunday night, it is around midnight or 1 o'clock in the morning, somebody has had a car accident and they come into hospital. They eventually end up in the ICU between 1 a.m. and 2 a.m. and they have had a catastrophic brain injury. They are bleeding and physiologically unstable. They might require emergency surgery, they might require a lot of products from the blood bank and there will be lab tests. This is very labour intensive, information intensive, complicated work to resuscitate that individual but they have a catastrophic brain injury and they are clearly not going to survive. Remember, it is Sunday night.

On Monday morning at 8 o'clock there will be several elective cases that will start in theatre and they will begin to operate between 7 a.m. and 8 a.m. You might expect by-pass surgery, head and neck surgery for cancer and that they will be back in the intensive care unit somewhere between 11 and 1 o'clock. So you have a situation where the intensive care unit is already probably full, maybe only has one bed available and that individual may be admitted into the last bed. So you have quite a complex logistical issue, which is organisation.

I might need to go in there in the middle of the night and I might need to ring a cardiovascular surgeon and say I would like him to start that case two hours later because we have a potential organ donor here and I want to sort this out with the family and I won't know necessarily for the next couple of hours. So it is very difficult.

If you do not have that embedded in your organisation of course what will happen is the people in the middle of the night will say that this is hopeless, this individual is not going to survive so unless there is a very strong advocate coming from somewhere from the family then that person will be treated palliatively, which is not ultimately inappropriate. They will pass away and the system won't be put under any further stress than it already is. So it is a low frequency event. As Kathy said, the issue is complicated. At crucial times appropriate expertise and seniority have to be available to deal with it because that person will then need to be examined by at least one intensive care specialist and have the forms and the brain death test done. As well, a small range of blood tests will have to be sent to hospitals and other tests that might need to be done for that individual to become an organ donor. So the sooner individuals start to think about that in the context of defined limits, the more effective the process is, but they have to draw a whole range of other parts of the organisation into that.

**Mrs RATTRAY-WAGNER** - I wanted to ask about the training of your medical staff. Can you give me some indication of how you bring your junior medical staff up to some level of expertise to be able to attempt to deal with what you have talked about?

**Dr O'CALLAGHAN** - Specific to the issue of organ donation, all intensive care trainees have to do the Adapt program, which is about end-of-life care and organ donation issues. That is a requirement from the Victorian Faculty of Intensive Care. It is only for intensive care training so that does not apply to training at the Royal Australian College of Physicians or the College of Emergency Medicine.

**Mrs RATTRAY-WAGNER** - Should it be, Gerry?

**Dr O'CALLAGHAN** - I think so. I think interested individuals should be supported from emergency medicine. I think it should be required for emergency medicine and then I think appropriate individuals from other specialities should be supported. At Flinders one of our neurosurgeons found it very helpful. We have a strong social worker presence within the unit and the social workers and the more senior doctors try I think to train the younger doctors in that issue. A lot of it is by exposure rather than formal training but it is difficult under the stresses of the public hospital system at the moment

**Mrs RATTRAY-WAGNER** - Finding the time to put aside for something that they may or may not ever need to use, I suppose.

**Dr O'CALLAGHAN** - The other thing I would have to say is that I think a lot of that training in terms of communication and sensitivity to the patient's wishes, the capacity to interact effectively, falls between the doctors and the nurses. I think senior nurses teach junior doctors an enormous amount about those issues.

**CHAIR** - Some have said that nurses should be involved in the process - and heavily involved - because the doctors are busy, running from one patient to another. The nurses probably have more to do with the family than the doctors. Therefore should it be the nurses who do the work that you have just described?

**Dr O'CALLAGHAN** - I think the nurses should certainly be involved. If anybody were to invoke the idea that the doctors are too busy to do this work I think that is to miss the point completely. What we are talking about is end-of-life discussions; it is about



palliative care. If you were going to have your tonsils out you would have a discussion about that with the doctor who was going to do it. I cannot imagine any circumstances in which it would be inappropriate for this to be done.

**CHAIR** - Do you find in some hospitals in some States doctors say, 'I'm too busy for this' and that is why you are talking about the culture aspect - which is terrific, it would seem, in South Australia - because they are doing other things?

**Dr O'CALLAGHAN** - I am sorry to be so repetitive but I think that it is ultimately about an end-of-life care issue and I just do not think that it is reasonable to be too busy for that.

**Ms HEE** - Can I say that I do not advocate at all the nurses being involved in this apart from caring for the family in an appropriate way that they would care for any family at the end of a family member's life. I think it is a very specialised area and I think that is where your donor coordinators come in to work with both the nurse and the medicos to support them with their expertise because that is what they do on a daily basis. That model seems to work better than just putting this on to a nurse. I totally agree with Gerry that this is an end-of-life care issue and it should be doctor-focused absolutely. I really disagree with taking it away from them because they say that they are too busy. I think the nurses have a terrific role in the whole process and part of that is that care that they get in the intensive care unit or in the hospital, as Gerry was referring to earlier, and making that process as smooth as possible for the family. Certainly we do include them if they want to come and have a family discussion. That is an important thing for them to do because sometimes it is very difficult for families to take in absolutely everything you say. It is good for the nurse to be there because if the family says, 'What did she mean when she said that?', the nurse can answer it. So there is a partnership arrangement but, again, this is what organ donor coordinators deal with 100 per cent of the time. They do not deal with anything else. That means that they build up a fair bit of expertise in supporting the doctors and the nurses in achieving the things they need to do.

**CHAIR** - Kathy, either you or Gerry were saying that in South Australia a senior doctor is the one who speaks with the family but also with the organ donation coordinator if possible?

**Ms HEE** - Not always. Some hospitals do that more than others and some doctors do not want us involved in that particular thing. However, we always go to the family at a later stage. We talk to them about exactly what is going to happen because quite often - Gerry is very experienced; he knows exactly what happens - you will get doctors who do not really know the detail of what is going to occur because organ donation takes a long time and you do not want to tell a family that you are going to have this patient in theatre in two hours when it is going to be eight or 10 hours before they get to theatre and then another five to seven hours in the theatre. They need to be fully aware of what they are agreeing to and they have lots of questions, such as whether the body is going to be disfigured and when the body can be buried. Those are the sorts of things that donor coordinators deal with all the time and that is where I see the role.

**Dr O'CALLAGHAN** - Often there is also an overlap between the coronial involvement, and the donor coordinator has a very good liaison relationship with the coroner's office and has a parallel channel, if you like, to the normal legal reporting circumstances of the

death. It is very important that that relationship is effective because otherwise the coroner may not give permission for the organ donation to go ahead.

**CHAIR** - What happens with that, Gerry, the forensic side of things? If a person has an accident and they are not too sure what occurred, the forensic people are there to ascertain the cause of death. If you believe there is also a real chance that that person is an organ donor, is there a priority or do you do it together or it doesn't occur?

**Dr O'CALLAGHAN** - The coroner has the last word. The coroner can say, 'I'm concerned' and not give permission. The coroner may order the attendance in some States and jurisdictions of a forensic pathologist at the retrieval operation for the organs. The next level down is that the retrieval surgeons may sign statutory declarations on what they find and a particularly detailed report of the process.

Often we find that there needs to be a parallel discussion between the organ donor coordinators and the coroner's office to us formally reporting the death and that precedes it generally so that we have an in-principle approval to proceed with the issue and also to advise the family. In those circumstances where the issue is brain injury then the coroner is happy enough to allow it to proceed.

Yesterday we heard about a recent case in New South Wales where -

**CHAIR** - Was that a gun shot?

**Dr O'CALLAGHAN** - The organ donation was not allowed to proceed and after quite a lot of discussion I think the individual was allowed to donate just a single kidney. The family was very disappointed because the coroner wanted to pursue a line for the autopsy. So that is an issue that needs to be addressed.

**Ms HEE** - I would like to expand on that because in South Australia in the 12 years of my job as an organ donor coordinator we have had two cases only where the coroner has said no and in both of those cases there were child protection issues involved. Generally - and I think this is what Gerry was explaining - the relationship between the agency and the coroner is of paramount importance.

We speak to them openly about what can be done. We have processes in place to ensure that the coroner gets the information that he needs. More generally in South Australia, if there is an issue he may say, 'You cannot take the heart', for instance, 'but that is all; you can take everything else'. Or, 'I would prefer it if you did not touch the head because we want to have a look at that brain injury'. So that relationship means that we can ahead in most cases.

**CHAIR** - Are you saying that in all of the cases where there is an organ retrieval or organ retrievals you have to make contact with the coroner's office?

**Ms HEE** - No, only in those cases that are deemed to be coroner's cases.

**CHAIR** - Who makes that decision?

**Ms HEE** - That is under the act which defines who, when, what and why. Of course we talk to doctors first but if we were a bit worried about that, the coroner's officers have told us, 'It does not matter, you ring us in the middle of the night and run it by us and we will tell you whether it is a coroner's case or not'. There have been a couple of instances where the doctor has said, no, this is definitely not a coroner's case and the coordinator has gone along with that and then we have found out that it was and the coroner really roasted the donor coordinators over that. So we always check with them if there is any doubt. But no, they are not always coroner's cases, although probably about 65 per cent, I reckon, are coroner's cases.

**Dr O'CALLAGHAN** - They changed the act recently to not necessarily include individuals who die within 24 hours of presentation to a hospital. I am unfamiliar with the Tasmanian situation. Prior to that a lot of these individuals with catastrophic injuries would have died. Anybody who is involved in trauma has to be reported. Obviously quite a lot of people present with stroke or brain injury. If they have any form of surgery they have to be reported and if they have any form of intervention then a lot of these issues are addressed with the intervention of radiology. Quite a lot of these people end up being reported and if they are reported then of course they have an autopsy and if they have an autopsy there is both delay in the family being able to access the remains and also it means that there is an inevitable disfigurement as a consequence of an autopsy procedure. So both of those issues need to be explained to the family as part of that end-of-life care issue.

**CHAIR** - It is a good way of putting it, isn't it, end-of-life care?

**Ms HEE** - It is end-of-life care. It is just an option.

**Mr HARRISS** - I want to try to understand better the catalyst for where you have been in the past. You have a perfect track record. What was really the motivation, apart from the obvious?

**Ms HEE** - How did it happen in South Australia, is that what you are asking me?

**Mr HARRISS** - Yes.

**Ms HEE** - It happened as a result of Minister Armitage visiting Spain. He was interested in the area of organ donation and he went to visit Spain. Prior to that one-and-a half donor coordinators situated themselves in a recipient unit, which is the very worst model you can have, let me tell you that. Never put your transplant coordinators or donor coordinators in a recipient unit. What the Spanish identified very successfully is that your donors come from ED and intensive care, but primarily from intensive care so that is where your focus should be and that is where your coordinators ought to be. Minister Armitage came back and we implemented in South Australia many of the aspects, not all of the aspects, of this Spanish model. There are some things about the Spanish. They use doctors only, for example, as organ donor coordinators. In this country we pay them too much. Basically that is the problem.

**Mrs RATTRAY-WAGNER** - Gerry may disagree.

*Laughter.*

**Ms HEE** - So what we did in South Australia was say rather than have just doctors doing this role of the donor coordinator, we will have donor coordinators and we will partner them with the medical person who is called a medical donor coordinator and who is part of the intensive care staff. So the one role that the Spanish had is actually melded into two, so he is at one end of that role and we are the rest of the role. We do everything that helps that the doctor in Spain would do. That model works very well for us.

There is also some, although now it's a very small amount, of money given to the intensive care units for their time and effort, if you like, but it's generally spent on people's education about organ donation. The role of the donor coordinator was then defined as providing education primarily throughout the hospital system. The medical donor coordinator does a fair bit of education with the doctors and they are responsible for getting policies and procedures in place for things such as donation after cardiac death, for example, which has its own set of problems. So, that money goes to education - post-graduate and under-graduate in the hospital setting.

The support of the donor family is another one of our very big roles. In South Australia - and most States have taken this on - anybody who becomes an organ donor gets linked into our services, and they are services that we provide for them - individual counselling either within the agency or externally with matters such as grief and loss workshops and a whole lot of follow up that occurs afterwards.

I think it is imperative for any successful program to have donor family care as a part of it because they can be your best advocates. If people are unhappy they will go to the media and give you a hard time and the donation rate will go down. The coordinators are part of one whole, if you like, and that system works pretty well, but the impetus did come initially from the minister.

We do things together like death auditing, for example. The donor coordinators audit the deaths in the major hospitals throughout Australia. When they come across a case when they think a patient is ventilated, has had a head injury, there's no mention here of organ donation brought up by the family, they will pull the file and have a look to see whether organ donation was mentioned. If it was not mentioned then that case will be brought to the medical donor coordinators who meet periodically and talk about these cases - how this should not happen in the future, and what things we can do to ensure that it doesn't.

Donor identification is a big one so that the organ donor coordinators are able to advise. If a younger doctor rings up and says, 'I'm not sure about this, he's got all of these other complicating factors. He looks like he might be a donor to me but he's shooting up drugs or he's got hepatitis B, or something. Will this person still be a donor?' So they can provide that kind of advice. In our system we just don't have enough donor coordinators to do the job we need to do because we don't really look at the country hospitals. We currently have somebody on board who's looking at that at the moment. We get an odd donor from the private hospitals but to our peril, I think we're losing donors in that sector.

The idea, I guess, is to identify every potential donor that we can, to make sure that organ donation is part of the end-of-life care. If they are suitable for organ donation, make sure that they are actually approached about organ donation, in 100 per cent of

cases; that's our aim. The next aim has to be to move 75 per cent of those families over to saying yes, and there is an area that I think we need to improve on because I think the Spanish utilise what they call 'designated requesters' so only particular people should ask. Now at the Flinders Medical Centre it is pretty much Gerry, but not all the hospitals -

**Dr O'CALLAGHAN** - No -

**Ms HEE** - Well all your senior people, your senior group of people - so they pretty much are designated requesters. There might be four or five with you but not many more than that. You do not send anyone else really out to do that, do you?

**Dr O'CALLAGHAN** - No.

**Ms HEE** - In the Royal Adelaide that used to also occur very much so there would have been a few little issues there; at that time it was anybody having a bit of a go at it and, guess what happened, the donation rate fell down. They are getting their act together again at the moment. That experienced person is absolutely important and the next stage is to actually support for your donor families.

**Mrs COLEMAN** - There is some anecdotal comment around nurse involvement in intensive care units and my understanding of that is that a nurse who may have had a conversation with the family in general terms about what might have been occurring or what might be occurring might have the family say to them, 'What about organ donation?' and that information would be fed through to the intensivist so that the nurse would hear the message or hear the approach and then it would be passed on to the appropriate person to manage.

**Dr O'CALLAGHAN** - I think at this point it might be appropriate to say that there is also an Adapt training program for the nurses, which is slightly shorter, and in the work we have been doing at the collaborative, one of the things that we have identified is that we believe that there should be a goal of having a certain percentage of nurses within an intensive care unit having done the Adapt program because then they know how to handle those questions and what to do with them, understanding all the circumstances in which they are relevant or not relevant. They certainly need to be part of the process and should not be excluded from it. But because of the logistical issues, if there is not senior medical ownership of the issue within an institution then it just will not happen and that, I am afraid, is the bottom line. I think the issue of private hospitals is interesting but probably there are only two or three private hospitals in the country that are big enough to actually generate the necessary circumstances because they have busy emergency departments, intensive care units, stroke units and that sort of thing. Some hospitals in the country that perform well have very high rates and some have almost 100 per cent of their nurses having done the Adapt training program and that goes right down to 1 or 2 per cent.

I think something that you could do that is really an inexpensive intervention, which I believe would have a fairly major result, would be to address that.

**Mr HARRISS** - I want to come back in a moment to the hierarchy in South Australia so I can understand how you have set it all up and so on, but just on that matter that Gerry has just

mentioned - and it goes back to the comments earlier that we are missing out on organ donation through the private hospital system - where does that sit though with your earlier comment, Gerry, that no doctor should be too busy to attend to this significant issue?

**Dr O'CALLAGHAN** - I think that palliative care is probably something that occurs well in the private sector but I think at the moment there is no funding mechanism for organ retrieval in the private sector. I think that the individual dying in the intensive care unit is not the problem and I think that the next stage of formally declaring that individual brain dead can also occur quite easily in the private sector, but it is after that things get complicated because then that individual needs to go into the operating room and have the retrieval surgery. An anaesthetist would need to be part of that process and surgeons and so forth and there is no funding mechanism nationally to do that. Now our DHS have found some money so that we can remunerate private hospitals when that occurs but the Spanish, for example, say that their view on this is that they just go and retrieve that individual back into bigger public hospitals. They say that it has such a big effect on small hospitals. You can have five or six teams of surgeons, a whole bunch of nurses and an enormous amount of equipment and they can use up all their scrubs, sterile drapes and operating equipment. They can leave the place incapable of doing any work for 24 hours, so it can have a big effect. I think that obviously the big private hospitals in Australia can easily absorb that activity. Again, I think it is just part of the culture. Private hospitals are all about efficiency and this is not an efficient operation. It slows everything down, it is about having time, taking time. It is very cost-effective in a broader to the health system in general but it uses a lot of resources in the short term. You have to do a lot of tests and investigations and it is quite intensive.

**CHAIR** - We have been told the savings are \$1 million per organ. Is that correct or does it depend upon the organ?

**Ms HEE** - A million dollars per organ?

**Mr HARRISS** - We were told that an organ donated would save the health system -

**Ms HEE** - How many organs?

**CHAIR** - That was never asked. I took it to be per organ.

**Ms HEE** - If you have a look at the kidney health web site, they have a breakdown of the cost - how much it costs to have a person on dialysis, and basically that is \$80 000 per year. If you take the two kidneys and transplant those, there is \$160 000.

**CHAIR** - Per year.

**Mrs COLEMAN** - Yes, but the dialysis cost is one cost, the surgery is another cost and then the ongoing medical treatments of that individual for a period of time is an amount of money that adds up. The last figures I saw were about \$80 000; then a subsequent cost of the first year after transplant, a certain cost; and then it dropped down to what might be \$20 000 to \$30 000 a year after that. We would need to do some work on getting you some accurate figures.

**Dr O'CALLAGHAN** - The in-principle issue is that people with these chronic conditions have multiple hospital admissions in addition to their therapeutic requirements, one of which is dialysis. When we have a transplant we have mainly outpatient interactions and drug therapy and they require far fewer admissions. Dialysis patients often require multiple blood transfusions, and that is their experience with drugs as well. Mainly multiple organ donors in Australia donate somewhere between about 3.5 to 3.7 organs per donor. That is an international standard and we do very well at that in terms of international comparisons. Then if you multiply that effect per organ for an individual donor it is a significant saving per multi organ donor. That supposes that it is a successful process with multiple organs for an individual.

**Mr HARRISS** - We have been talking about the costs and the benefits and data, have you analysed the savings long term to the health system?

**Ms HEE** - No, that's not our role. That's something we could provide.

**Mr SLATER** - We have certainly done research on that and, as Marcia said, we have a report that has a look at the economic costs and benefits, which we can make available to you. There are quality-of-life issues that go with this, too, of course. There are some very good economic studies around what the impact might be in terms of quality-of-life benefits that flow from these interventions as well.

**CHAIR** - You have a report you can give us on that?

**Mrs COLEMAN** - Yes, we can. It's not only the individual; it is also the extent and the social cost.

**Dr O'CALLAGHAN** - There is an international dataset on quality of life, transplant and post transplant, et cetera, so there are international comparisons and different strategies about, for example, whether you do a renal plus a pancreas transplant. We are really involved in the donation area so that is where our expertise is.

**Ms HEE** - The big thing, I think, is that most of the money tends to go with the transplant side because that is where you see all the happy stuff and people forget that you cannot have all the happy stuff without putting money into the donation side. I think we have struggled with that in this country for a long time and it is time that the balance shifted a bit more towards to the organ donation side. If you asked me how would you fix Tasmania, the very first thing I would do is do what we have done in South Australia and that is appoint some organ donor coordinators.

**CHAIR** - I will ask you that before we finish.

**Mr HARRISS** - On that, Kathy, because you have been successful in South Australia based on the minister's genuine interest some years ago, what is your structure from the top downwards?

**Ms HEE** - Originally or now?

**Mr HARRISS** - Probably now, I guess. You have learned lots along the way.

**Ms HEE** - Originally we had a medical director who had a lot of clout in the community. He had been the Dean of the Medical School. Then there was a manager and then, under that, donor coordinators and beside us, medical donor coordinators. So each of the major hospitals, Flinders, Royal Adelaide, Women's and Children's and the Queen Elizabeth, were appointed a medical donor coordinator. Now it is a little different. We do not have a medical director at the moment, but there is money apparently coming back into the system for him. They are useful particularly when you are setting up because they are the people who break the ice with the intensivists and the ED doctors around the place. So if you are thinking about appointing somebody, make sure it is somebody who has the respect of those people because that is how you break the ice initially.

There is the manager, who currently is me, and then we have four donor coordinators in South Australia. We only started off with two and we now have four.

**Mrs RATTRAY-WAGNER** - Soon to be five, with the new hospital?

**Ms HEE** - I hope that we will soon have five but we have to convince the minister of that. But our minister seems to very supportive so hopefully this will occur soon because currently we have this person as a relief but it is not enough because your donor coordinators get really tired. Coordination is one of those areas where you can be really overwhelmingly busy and then nothing will happen for 10 weeks. You say, 'What do you do in the meantime?' There is promotional work; there is going out to schools; there is community talks; there is death auditing -

**Dr O'CALLAGHAN** - Visiting families. That is where we spend a lot of time, following up families. We drive down to Victor Harbour, visit families and spend time with them, and that is very important.

**Ms HEE** - They are our greatest advocates because the donor families are the first ones to say, 'They were wonderful to us and they gave us such a lot of support'. They are great advocates for you and what is more, they advocate in their own community; they will say it was the best thing they ever did and this is the reason. But they will not say that if you just drop them and walk out the door.

We were originally owned by the Department of Health but had a separate space. We were reviewed a number of years ago and we now sit under the Royal Adelaide Hospital. However, we also still have our separate space. That is seen as being important in our State because it means that we are seen, even though we belong to the Royal Adelaide Hospital, as independent and so available to everybody, not just the Royal Adelaide Hospital, and that seems to work pretty well just having that agency. It does not really matter who owns us because half the time you report to the Department of Health and half the time you report to the Royal Adelaide Hospital. The Department of Health had a bit of a problem with our clinical side. They did not seem to understand clinically what we did and the Royal Adelaide does not seem to understand the politics involved in the national arena but that is okay. That is the structure at the moment.

**CHAIR** - With a lot of deaths, as you know, you have the initial flurry of people coming around sympathising with you, three or four months down the track it starts to die off a bit and a year down the track people move on. How often do you keep in contact with the donor family?



**Ms HEE** - Our care begins at the very moment that we talk to that family and at the beginning we always offer them a viewing, for example, if the family chooses to see the patient after they have been to theatre because a lot of them want to be reassured that we are not cutting the body up, for example. The donor coordinators wash the body and present the patient, stay with the family and prepare them for what they will see. If that does not occur we will always ring family the next day and tell them which organs have been taken and if there were any difficulties or problems.

We write to the family and most States do this now. At two weeks they will get a letter and a bereavement package which has information in it about grief and loss, about organ donation, about the special issues relating to organ donation, and they are told about the outcome of the recipients. We would give them information such as their age and gender and a little bit about who they are. We do encourage, through the recipient coordinators, recipients to write to donor families anonymously. That is a very important part of their coming to terms with their grief.

We have a second bereavement pack that we send out at six weeks. This is the formal stuff I am telling you about now. You get quite bonded to your donor family so you get a sense for how much they want you to call them. You can ask them that. For some families it is quite a lot; some families you might call every second day or once a week. Other families want your support but they might have other problems. We might visit them and, again, it depends on what else is going on for that family. Sometimes the situation is not just about the grief and loss, it is about other issues.

We offer formal counselling through Oak House Services, so if they need formal individual counselling we have psychologists who provide that.

**CHAIR** - Who pays for that?

**Ms HEE** - We do.

I have a social worker on board as one of my donor coordinators. I am a nurse and a social worker. Periodically we would send out information to donor families and say we are running a grief and loss workshop. We generally run those in hotels because donor families have said they would rather have a day than an ongoing support group. We provide food for them and we will run a structured day for them. It is focused on not only loss and grief but also the special issues relating to organ donation. We are very careful about who is in those groups. They tend to be quite small so that we would run special ones for families who have lost children, others for families who have lost partners and the last one we ran was for younger folk in the family where there was a sibling lost. The issues are different.

Once a year there is a rose-planting ceremony at the beginning of Australian Organ Donor Awareness Week and then, of course, there is the annual thanksgiving service which is run around Australia. That is the program that we have and it is more or less involvement depending on what the family wants. Some families say that is enough, they do not want any more; others will want you to be with them for fairly long periods of time.

**Mr HARRISS** - What is the sensitivity between recipient and donor family contact? How do you handle that?

**Ms HEE** - You are probably asking the wrong person here because everybody else in Australia will say, 'Oh, it shouldn't happen', but I think it should. I shouldn't say that. I think there needs to be a mechanism in place that allows it to occur if both parties want that and if both parties have been counselled through the process, why do you want to do this, and have thought about issues such as this person might not be what you've built up in your mind. What if this person is Aboriginal and you've got a problem with Aboriginals or Asians, and so on?

I think what happens now is really ad hoc, and I think it's wrong because what the health professionals have said is, 'No, no, we once had a case where a donor family stalked a recipient'. I don't think you can build up your whole environment on the basis of one case. I think what is occurring at the moment is that donor families and recipients are meeting informally. Very often they are introduced by journalists who want the moment on television, the crying and all the rest of it because that's good copy. I think we are letting them down. I think there should be a mechanism similar to the adoptions thing. That's what I would advocate.

**Dr O'CALLAGHAN** - I think that it's a particular issue in small places, and Adelaide is a small place as is Tasmania. I think it's pretty tough to avoid it. It doesn't take much for families to figure it out.

**Mr HARRISS** - I could imagine if I were a recipient I would want, with all of my heart, to say thank you to the family of the deceased donor. If they don't want it, that's fine, but gee whiz, you'd want to go and say, 'I've got a quality of life because ...'.

**Ms HEE** - As Gerry's pointed out, people need each other. We've had a number of cases where somebody in one street has died and somebody in the same street has received a kidney.

**Mrs COLEMAN** - In Victoria contact is facilitated - not direct contact - through a sharing of letters and so on. The recipient might write to the agency and the agency will pass that on to the donor family. The donor family might want to write to the recipient and that will be passed through. That could happen in numerous circumstances on a lot of occasions, so I think you will find that what might occur in South Australia and possibly in Tasmania could be quite different in the larger jurisdictions. Some of the agencies have quite rigid, I think, views about it, don't they.

**Ms HEE** - They do. Some of them have very rigid views, but I'm a great believer in self-determination. Maybe that's because of my social work background; that's because I'm a Catholic. I'm not quite sure, but I think self-determination and autonomy are what we talk about a lot in the health system, and yet this is one area where we don't allow it to occur. We do allow the exchange of letters, obviously.

**CHAIR** - How is the National Collaborative going? How has it helped? Is it going to continue to help and in what way?

**Ms HEE** - I think the National Collaborative has been fantastic, I think it has really spurred the sector on. We had been experiencing a bit of a depression here in South Australia for a whole range of reasons, but it provided that impetus again, got people's enthusiasm back and helped us to re-establish links. In some instances in interstate areas I think they have established links for the first time. I see it is a fantastic thing, just wonderful, and I would love to see it go on, but that's just a personal thing.

**Dr O'CALLAGHAN** - I think the collaborative is helping. It needs I think to be a fully national project to take it to the next level. It has helped a lot by identifying the fact that there are clear differences in practice across the country. We have established that, with major differences in outcome and consent and for referral rates and we have identified differences in practice and in culture. We have identified a whole network of people across the country who are willing to take responsibility for this activity. We have educated those people so they are more confident and more knowledgeable.

**CHAIR** - It should be consistent Australia-wide, shouldn't it?

**Dr O'CALLAGHAN** - Yes, it should and I guess that is the next challenge for it as a project. I think there is broad support and both Federal and State levels support it in the longer term. Our clinical practice improvement program is about engaging doctors and nurses in hospitals and helping those doctors and nurses interact with their organisation in an effective way to get the space and resources that they need and the support that they need to do their job in this area better. I would be happy to answer some specific questions.

**CHAIR** - I was doing a case once and it was on a person who died as a result of getting an injection. We did not know whether it was a deep sleep treatment as in the Chelmsford Hospital or what. The case went for about four or five days and one of the nurses came up to me in the end and said, 'Look, you should have asked me a couple of more questions' and I said, 'Well, it's like trying to find a needle in a haystack. What do I ask? It is up to you to come forward. I'm not being critical but you tell us what you think we should know, rather than me going on a fishing expedition.'

**Dr O'CALLAGHAN** - What I think you should know is that the best thing about it is that it has been about safety. In each hospital there is a doctor, a nurse, an executive sponsor and a project officer and that project officer is somebody who has a day or two a week. There have been some changes but effectively they have some time to work out within the hospital with the other members of their team where they are at, what needs to be done and they start measuring their performance and then they submit that measurement as part of the national program. Australians Donate takes that information and then we present that back to the other hospitals in the project and so people can measure how they are travelling and they can compare that measurement to how other people are travelling. They do not identify with hospital *x* and hospital *y* but we know that this is how the hospitals within the collaborative are travelling and we can see the spray of activities in terms of high achievers and low achievers and then the people who do things well, they take those different things that they have done and then they bring that back to our various learning sessions. At each learning session we all share stories about successes and then we share difficulties and challenges and talk about them and do some quite structured work with clinical improvement and methodology experts about how we improve our practice.

That whole process has given initiatives and a mechanism of recovery for quality improvement that we did not have. There is a planning group who works with Australians Donate to provide advice about where we think the project should be tweaked in order to do this or that or involve different people or whatever. On many occasions information from experts from a North American collaborative has been very helpful, although they have a slightly different language and flavour to us. Some of that has been very inspirational and they very much challenge some of the preconceptions that we have about what our expectations are of ourselves and each other. It's been quite interesting. That is the sort of journey we're on. We are now 18 months into it, so we have done quite a lot of work. I guess now our challenge is to take all the work we've done and try to present it in a coherent and tangible way so that it can be shared with other people. Yesterday, for example, we heard from the chaplain from the Westmead Hospital in Sydney about how they engaged with religious leaders from right across the sector, brought them into the hospital, got involved with organ donor coordinators and clinicians and people from the collaborative. It demystified the intensive care. We took them around the ICU and identified people from different religious groups they could go to if there was confusion about whether this was permissible or not for their religious faith system and the chaplains communicated with each other on these issues.

There have been an enormous number of problems addressed right across the country. We have made some uniform progress, I think. There's no doubt about it, the context of the discussion from people who are involved in this process versus people who aren't is very different. Yesterday we had some new teams come along and it was very interesting hearing them talking about the issues as everybody else was talking about them 18 months ago - the vocabulary, the lack of capacity to understand some of the issues, their timorousness or lack of confidence about being able to address some of the issues. This project has given a lot of people a language, a vocabulary and the confidence to talk to their own organisations and say, 'It's all very well to say that you want us to do this, but these are the things we need in order for us to do it better. We believe these are your responsibilities in this issue. We're comfortable with ours but we don't believe as an organisation or a jurisdiction that you're coming to the party'.

It is a big project because there were 20 hospitals - I have done 22 hospitals in the first year - and now we have 26 hospitals. Two dropped out, mainly for volume reasons, and we have had six more join. It is now really a big project. I believe the two things that really need to happen is that it needs to come down to a budget and I think we need to have a nationally-consistent metric, that we are all measuring and comparing the same things. Effectively we have been using a version of the APODD audit from Victoria, which was designed by Bill Sylvester and Helen Opdam. Helen has been part of the planning group from the beginning. I think that is a very good foundation. There are things that may change but it has been a very effective way for us to say we are all on the same page.

**CHAIR** - In Tasmania, what recommendations do you think we should be making?

**Mrs COLEMAN** - In relation to?

**CHAIR** - In relation to organ donation and the terms of reference.

**Mrs COLEMAN** - I just want to touch on the collaborative, if you don't mind. I think it is important to understand the potential for scope of the collaborative across the country. I want to put into context the way we arrived at 22 hospitals in Australia as the first participants in the collaborative. We identified 29 high-performing hospitals across the country that ought to be part of the collaborative, we thought, in terms of the potential for organ donation, the experience that the hospitals would have accumulated, or would potentially accumulate, in the context of organ donation such that they had a good body of experience. In the end we were funded for 20 hospitals to join. That was as much as we could afford. We pay the hospitals \$40 000 as a contribution towards a project officer part-time, or anything else that they want to use that money for. We pay for the travel and accommodation and the improvement advisers and all of the extras on the web site that go into a project. We had limited funding. We managed to squeeze in an additional two hospitals because the intergovernmental committee recommended that we ought to have not only the high-performing hospitals but lower-performing hospitals as well so that we could look at the contrast of the lower-performing hospitals. We were a little reluctant to include the lower-performing hospitals because we had limited resources and a new activity that we needed to imbed and we needed to have people learning, so how much resource should we put in initially, but nevertheless we ended up with 22 hospitals.

We especially wanted Tasmania and Queensland to be part of that and Queensland had gone down the route of appointing medical donor coordinators and felt that that was the task that they had undertaken, that was the commitment that they had made financially and they believed that they would proceed that work before becoming engaged or considering involvement in the collaborative.

In the context of Tasmania at that time I personally approached all the hospitals that were interested or that we thought should be interested in the collaborative to test their receptiveness or otherwise in order to be a little persuasive about them joining. Tasmania, of course, was one and I spoke to David Boadle down there. He felt at the time that the Royal Hobart had lost a key person, things were a little disruptive down there and then was not the time for them to become involved.

We subsequently invited anyone who wanted to come from Tasmania to observe the collaborative through David Boadle so that they could have a look at it without committing, so that was the circumstance with Tasmania. Nevertheless we went ahead with the 22 hospitals.

More recently we sought agreement from the Federal minister and the department of Health to expand the collaborative to an additional 10 hospitals. The department was somewhat reluctant to engage in an expansion of the collaborative. They would have preferred that there was the one-year collaborative, then an evaluation, and then, if the evaluation showed it all to be okay, perhaps there would be another collaborative. We fought fairly hard for a continuation of the collaborative into a sustainability model for the 22 hospitals that were initially in it because what we had seen or what I had observed in North America and the collaborative methodology experience around the world is that you cannot run a one-year project then dump it because you lose the impetus, the learnings and the momentum that have been gathered in the period of the year. So we pressed extremely hard to get a budget for the sustainability activity to continue. That is what we are on now and that is what we started really in July.

In pressing for the spread to additional hospitals, the department was somewhat reluctant about that as well but fortunately the then minister was quite supportive so we achieved funding for an additional six hospitals and went through the process again, approaching the surgical six hospitals and that included Orange, Wollongong, Royal North Shore, Monash Medical Centre, Dandenong Hospital and Lyell McEwin Hospital. So those six hospitals came to their first meeting yesterday.

The point that Gerry was making that I would reinforce quite strongly is that this is a national project that we would hope that Queensland and Tasmania would be engaged in to bring about the full benefit of the collaborative methodology, the collaborative work which is about changing practices within hospitals, and that place is the only place where organ and tissue donation is going to improve and be acted upon. So hospitals are the key, and hospital staff donor agencies are the key to lifting organ and tissue donation rates around the country.

**CHAIR** - So that should be a recommendation, you believe, that Tasmania should become part of it?

**Mrs COLEMAN** - Absolutely a recommendation that the collaborative is continued, that it is a national project, as you have mentioned and we reinforce. It is incredibly important for a commitment to that if it is to occur and that that commitment is made soon because we have within our jigsaw, if you like, a whole host of energetic, enthusiastic people who are in a learning process and getting to 31 March because that is when is AD is funded to, and then having ARMAC consider whether not funding will occur and then maybe commencing funding in June or July would create of hiatus that would be significantly detrimental to the collaborative. So we believe it is of fundamental importance for it to be a very quick decision about ongoing support for the collaborative with a funding allocation in order to achieve that.

I have been on my high horse and I apologise for that but when you have a successful project that achieves a 32.4 per cent increase in the donation rate in the collaborative participating hospitals in a year then that is extraordinarily impressive. If you look at the average of the improvement in donor rates across the collaborative hospitals over five year then it is a 25 per cent increase. If I applied that same mathematical logic to Queensland where they did have one outstanding year, the increase in the donor rate over the average of five years is 2.6 per cent. It is a very telling statistic that we really need to take note of.

One other thing that I would not mind saying, Jim, if you will indulge me?

**CHAIR** - Yes, please.

**Mrs COLEMAN** - I can say that the collaborative is hugely successful, should be ongoing and needs solid commitment from around Australia. We believe that, anecdotally - we have had no written word - all Health ministers support its continuation. But then the timing is critical for that commitment to transfer into action.

I want to talk briefly about the New South Wales Road Traffic Authority Register and the Australian Organ Donor Register and the complications that occur when there is

more than one register to access. In 2005 all Health ministers agreed in a communique, and I was on the working party of that, that the Australian Organ Donor Register should be accessed in all cases where a potential organ donor is identified and that communique was signed off. We included that request in the methodology for the collaborative. However, when ministers say things, it does not necessarily mean that it transfers into action in hospitals and there are a lot of processes that occur, such that people determine within their hospital whether that is appropriate for the hospital to take on board. I think that is a judgment that hospitals need to be able to make, particularly in terms of the timing of when they might access, for example, the Australian Organ Donor Register. But the Australian Organ Donor Register, more recently, since 1 July 2005, became a consent register. So we have a body of intent and a body of consent, altogether 5.6 million people or so who have registered an interest in becoming an organ donor.

The RTA, the Road Traffic Authority Register, have a very large body of people in New South Wales who registered when they signed on for their licence but there is very limited information, with a small box in the last right-hand corner of the application form, 'Do you want to be a donor or do you not want to be a donor?' There are about 30 per cent of the donors that are on the Road Traffic Authority Register who have registered a 'no' and the majority have registered 'yes.' The information that they were provided is not fulsome, therefore the organs that they might wish to donate might not be as well specified as other documentation. It is considered by New South Wales that a road traffic authority registration is a legal consent and a 'no' should never be challenged. So a 'no' is a 'no' and cannot be changed even if the family have indicated that the family believes that this person has changed their mind and wants to be an organ donor. The consequence of the 'noes' has meant that in the last year New South Wales have lost eight donors. The Road Traffic Authority Register has said no. The family has said, 'But I believe they changed their mind and this is what they would wish to do.' But the New South Wales department sees a 'no' as a 'no'. The Commonwealth say that the New South Wales 'no', is not such a no as people would suggest, so you know what lawyers are like.

*Laughter.*

**CHAIR** - It sounds like a court case; you think you know when a 'no' became a 'yes'.

**Mrs COLEMAN** - But in New South Wales the staff have to access not only the Road Traffic Authority Register but then they have to go to the Australian Organ Donor Register because a person might have registered a no with the Road Traffic Authority and a yes on the AODR, but the Road Traffic Authority prevails. There is enormous complexity around this, and the contractual obligations between the Department of Health, Medicare and the Road Traffic Authority enabled one download or upload of registrations onto the Australian Organ Donor Register, and did not enable through a loose decision - and I need to say it's a loose decision because they couldn't find the decision when we challenged it - that the noes ought not to be uploaded onto the Australian Organ Donor Register. So there is enormous complexity.

The RTA stuff hasn't been uploaded since late 2004, so there's nearly three years of registrations that are not on the AODR. So it's not quite as picture perfect as one might think, and I thought you should know that.

**Mr HARRISS** – Marcia, during that presentation you said that Australians Donate is funded until March, but there's no guarantee of a continuation. Is that what I understood you to have said?

**Mrs COLEMAN** - Yes, that's right.

**Mr HARRISS** - There's going to be some reassessment?

**Mrs COLEMAN** - Well, I think it's a little more serious than that. We had a presentation by the Department of Health and Ageing on 24 October which I am happy to pass on to you for you to have a look at. It is AHMAC's governance review of the organ and tissue donation sector, October 2007, and in this, senior officials met and determined a governance model for the sector which involved a cognate committee on organ and tissue donation.

It is quite a complex committee which some might say - and Kathy's probably got a view about this - is a revisit of what used to occur in the past - that is, that there is an organisation called CORD I, CORD Mark II, CORD I reviewed, CORD Mark II reviewed, Australians Donate reviewed, Australians Donate formed under articles of association, another review, and maybe a cognate committee on organ and tissue donation to be established. The complexity of that model is before you there.

I have a copy of the paper that recommends that there ought to be no place for a non-government organisation in that model, so therefore funding for Australians Donate is due to cease on 31 March. If the senior official's recommendations are accepted and there's some question mark about that for two reasons - one sector largely doesn't like the thought of a cognate committee; it doesn't know what it means and thinks it -

**CHAIR** - I was going to say what does a cognate committee mean?

**Ms HEE** - I think its something for saying that you're not supposed to be doing the work.

**CHAIR** - That sounds like a parliamentary term.

**Mrs RATTRAY-WAGNER** - Where is the funding for those 22 plus six more hospitals?

**Mrs COLEMAN** - The contract with the hospitals ends on 31 March unless there's a formal commitment with funding to go with it for the collaborative to continue. That's the point that I was trying to make very strongly. In relation to the presentation by the department, it's going through a process or has gone through a process of consultation. It was due to go to ARMAC at a session.

If the Health ministers were due to meet on 7 December, and there is some uncertainty as to whether or not that might occur now, then they would agree to either the cognate committee or another model, and then they would make decisions presumably about a continuation of a non-government organisation beyond 31 March, or otherwise. The reason I am pointing that out to you is that it is very much on the agenda at this point in time.



**Mrs RATTRAY-WAGNER** - Mr Chairman, I have a question about online donor registration and I noticed in your submission to us that there is a component of online registration. I was of the understanding that online registration was not available so can you just tell me where I misunderstood that?

**Mrs COLEMAN** - Online registration is available but then there is a confirming letter sent to people to assure them that the registration - Terry might comment on that.

**Mr SLATER** - I think it is about the consent intent when you register online and there is an issue around consent so I think the follow-up letter is more of a legal document which gives the legality around consent and so that is an important follow-up in the step.

**Mrs RATTRAY-WAGNER** - So it is almost just an inquiry really on behalf of somebody and then they will get the following documentation as a person who has filled out one of these particular forms?

**Mrs COLEMAN** - Yes.

**Dr O'CALLAGHAN** - There is a figure of 2 per cent nationally for that form returned. If you returned it then we would be able to access or the organ donor agency would be able to access an intent on the register which would be enough for us to inform their surrogate decision makers and ultimately they would make the decision anyway. Strengthening the register with a consent register by having a signed consent with a follow-up letter or having done that in the Medicare Office informs that decision a little bit better but ultimately it does not change anything because the practice nationally is that if there is a sincerely held objection or if there is a significant objection from a close member of the family or their support group in the lack of blood relatives being available then organ donation would not proceed, almost certainly.

There is one issue that you have not touched on this morning and I am not sure that this is the group to go through it with you but I think you probably do need to have some discussions about the role of the designated officer in Tasmania and I do not quite know how that sits within your legislation.

**Mrs COLEMAN** - What we could do is provide you with the scoping study for human tissue acts across the country and the differences between them and that might be beneficial in that it could highlight the roles, so we will send that to you.

**CHAIR** - Great.

**Mr HARRISS** - I do not know that there would be any legislative control specifically on the position that Gerry is talking about, with some sort of coordinator. Wouldn't that just be an administrative process?

**Dr O'CALLAGHAN** - No, a designated officer is an individual who, on behalf of the hospital or the organisation, gives permission for the remains of the deceased to either have a post-mortem or for organ tissue donation to occur. The family have no control over it in a legal respect. The role differs widely across Australia. There is quite a deal of complexity in how that role is realised across the country and Tasmania would have some similar arrangements that I am not familiar with.

**CHAIR** - It is the first time that it has been brought up.

**Mr O'CALLAGHAN** - It can be a real speed hump.

**CHAIR** - With those terms of reference, are you able to give us a thumbnail answer in relation to each of them? I think they are pretty well self-explanatory to some degree when you have sat through the evidence that we have.

**Mrs COLEMAN** - In relation to number one, if you have licence registration they should be uploaded quite readily. There might be some technical issues in terms of the computer programs to enable that to happen but it really should be possible to do it.

**CHAIR** - Some argue privacy laws.

**Mrs COLEMAN** - Let me just challenge that.

**CHAIR** - Yes.

**Mrs COLEMAN** - We are advised that the New South Wales Privacy Commissioner had agreed that yeses could be loaded onto the Australian Organ Donor Register but the noes could not. I am not a lawyer but that response just seemed so illogical. When I challenged them, they couldn't find the decision around the noes. There is a new privacy commissioner in New South Wales who is enabling the noes to be uploaded. I suspect that one of the reasons why the noes weren't uploaded was because it might have prevented an approach to a family and the Road Traffic Authority was due to be wound down. That is what I suspect.

There should be no reason why registrations in Tasmania should not be uploaded onto the Australian Organ Donor Register. Per head of population Tasmania is enormously supportive of organ and tissue donation.

**CHAIR** - One-third.

**Mrs COLEMAN** - Yes, absolutely. It just seems illogical to me that it wouldn't be uploaded.

**CHAIR** - I agree with that.

**Mrs COLEMAN** - The adequacy of Tasmania's approach in identifying potential donors and so on is really a LifeGift issue. LifeGift, as you know, operates the agency in Victoria and New South Wales under the Red Cross, contracted by each of the departments. One tends not to want to be questioning, but New South Wales and Victoria have the poorest donor rates relative to their population of any of the jurisdictions in the country. They are two States where the donor rate should be much greater, and one ponders that. Because Tasmania comes under LifeGift in Victoria, my view - and this is a personal view -

**CHAIR** - If you want to give any evidence in camera you can. I should have mentioned that beforehand.

**Mrs COLEMAN** - No, I am quite happy to say this. I think that the evidence is that a donor coordinator in a hospital is uniquely placed to assist organ and tissue donation processes through the hospital. I am quite happy to publicly say that. I think the evidence is there.

**Ms HEE** - I would agree with that. The Northern Territory has fewer people living there than you have in Tasmania and they have an agency. They have an organ donor coordinator and a reliever for that coordinator. That wouldn't be precisely the model they have set up. If you're going to think about what you ought to be doing, I think you do need to appoint a donor coordinator. If I were you, I would be appointing a medical donor coordinator as well. That is the very minimum, because you have the Launceston hospital in the north of the State, so you really ought to be thinking about somebody in the north and somebody in the south looking after those hospitals.

**CHAIR** - What has been discussed is having a coordinator in the north and one in the south, but a medical coordinator hasn't been looked at by this committee because you're the first person who has brought it up. You think that would be worthwhile?

**Ms HEE** - I think it would be very worthwhile. If you're going to go ahead with this, it is a good time because we have a training course for donor coordinators. We run it in South Australia and it's occurring in May. It is a week-long, live-in course where they are trained in every aspect of organ donation. It gives them a really good basis.

**CHAIR** - Is there a full-time job in Tasmania?

**Ms HEE** - Oh, yes.

**CHAIR** - We have been told maybe you could do it in a day or two days a week.

**Ms HEE** - I think it's a full-time job. It depends what you want them to do. Education is a big thing - public relations. The person you appoint needs to have some skills in that area. Once you start getting a group of donor families happening, there will have to be all the support that occurs with that. You'd be surprised, getting processes and policies and all those sorts of things up and running in your hospital takes time and effort. You should be involved in the national collaborative and that also takes up time and effort. There is a whole range of national things that the donor coordinators need to be involved with because it is not just a State thing. We exchange organs all the time, which means that we have to be a part of that national process. Donor coordinators are involved in writing national guidelines and all those sorts of things. Donor coordinators are not that expensive and I think the return on your money is money well spent.

**Dr O'CALLAGHAN** - It certainly would be a full-time job for the first number of years I think.

**Mrs COLEMAN** - One other thing that we could say is that I would contrast the South Australian agency with the LifeGift model in Victoria and New South Wales.

**CHAIR** - It seems to me that there is a question mark, you are saying, over the LifeGift model? Tasmania, because of its size, is with that model in Victoria. Are you saying

that there should be a consideration that it should stand alone and become part of the National Collaborative, which would be of more assistance?

**Dr O'CALLAGHAN** - The national program is for people who are already involved in this sector by virtue of being employed either by an organ donor agency or by a hospital. So, in our hospital, for example, the project officer, the person who coordinated the project was an organ donor coordinator who spent two or three days with us and as part of that role. So it was possible to combine that. But ultimately the State has to have an organ donor agency and it has to have doctors and nurses who deliver the care and then they can all cooperate together in a participatory program like the collaborative and that helps to identify what the issues and the problems are and devise some strategies to improve them.

How the organ donor agency should exist in a particular State is quite a complicated issue and a lot of it is about resources. The bigger States are probably, I think, underresourced to some degree. But they do not fundamentally have a philosophy whereby they send the donor coordinators to specific hospitals for an allocated time and they do not have a philosophy whereby an individual donor coordinator is associated with one particular hospital and its work force. So they say, 'You ring us when you have a potential donor and we will send somebody down.' It could be anybody. We may not know them. Then they have an increased level of complexity because there are State donor coordinators in that area and those individuals are employed by the hospital. So, New England, Prince Alfred, Westmead - already New South Wales have a different model. So the issue is whether or not the organ donor agency in an individual State should be a completely independent organisation, should sit within the DHSS, should be within the auspices of a hospital or should be part of the Red Cross. So they are the four different models that are currently being worked on.

I think it is a pretty complicated choice and there are pros and cons to the different models. But I think the fundamental issue is in the donation side of the process and that is a philosophical one and one which we believe the collaborative can support. But the most effective way is for the organ donor agency, however that is organised, to commit to an organ donor coordinator spending time in particular hospitals and being involved in the education audit and in clinical practice improvement; that they are there on a regular day or two a week so that the nurses can go and talk to them, and the doctors can also go and talk to them and provide information; and that they perceived as being part of the team of that hospital - they liaise with the emergency department, cooperating with nurses and they are not identified as being external.

**CHAIR** - I understand.

**Ms HEE** - The other thing that is worthwhile bringing up because I think it is really important - and we have not done it here ourselves - is involving the hospital hierarchy and getting organ donations as part of the KPI of your hospitals. That is a really important thing to do. You need both a top-down and bottom-up approach for this to work.

**Mr SLATER** - There is data available which looks at the different models of how they have performed since they were adopted. There are two States where, since an organ donor agency has been introduced, there has been a significant fall in organ donor rates - that is

New South Wales and Victoria and they use a different model from the rest of Australia. Their performance relatively is poor. In absolute terms they have had an absolute reduction in organ donor numbers that they have been able to collect.

**Ms HEE** - They are both under Red Cross and they do exactly what the Spanish say you should not do. They sit in their office and they wait for somebody to ring them up. The Spanish say that if you don't want to have an organ donation rate that is what you do.

**Mr SLATER** - That's the LifeGift model.

**CHAIR** - You believe a coordinator would -

**Ms HEE** - Be of great help.

**CHAIR** - be of great assistance to cope with that?

**Mrs COLEMAN** - Yes I do. And I think the other issue that you might want to look at in concert with that is which of the policies of the LifeGift model are appropriate or inappropriate if you want to have a very active organ donation project within the State. I have sat on a review of the LifeGift model in New South Wales. That is a public document and the recommendation was that it ought to go out to tender and it ought to be placed within a hospital or a region, but they have not acted on that at this point in time and they might not. From AD's point of view, there some issues with the model that is currently in use in Victoria and New South Wales.

**Mr SLATER** - And the two best performing models. By far South Australia is the best -

**CHAIR** - And the West Australian?

**Mrs COLEMAN** - Yes, fantastic. Well supported by the ministers, very active and doing a wonderful job.

I hope we have not complicated things too much.

**CHAIR** - No, that's interesting, thanks. Two of the things that you raise - the internal coordinator for the north and south, and that has been mentioned by LifeGift as well, and the KPIs in relation to proper auditing to see what you miss, if you do miss why you miss it - would be more than beneficial for Tasmania. So that is a fairly common theme in relation to the evidence that we have received. That is good, thank you.

The only thing I was going to ask was whether the collaborative report would be coming down in December?

**Dr O'CALLAGHAN** - I think you mean the report of the national task force.

**CHAIR** - I am sorry, that is what I do mean.

**Mrs COLEMAN** - It absolutely is. The final meeting is on 11 December.

**CHAIR** - That then goes to the minister. Do you see that?

**Mrs COLEMAN** - I am a member of the National Clinical Task Force and so is Gerry. We have not seen the final report at this point in time - or at least I haven't - and we expect to see it and either agree or disagree or comment on 11 December. Then it will go to the Federal minister.

The National Clinical Task Force is a creature of the Commonwealth Government and Minister Abbott and the timing of that was very interesting because we had pushed for the National Collaborative, which came into being in June. We had worked on the development of that project over a period of time and sought funding. Then there was the budget measure, a budget allocation of \$23.4 million, in May last year. So the department was working on policy direction from about September 2005 in order to arrive at a budget measure to be announced the Budget in May 2006. With the collaborative project, we started working and observing, and made decisions about pursuing that in October-November 2005. We got final approvals in February-March 2006. So you can see the processes were running in parallel, and you know the dilemmas around parallel processes and how on earth do you bring them together such that there's a sensible outcome in the longer term. So they have continued to run in parallel. The National Clinical Task Force likes the National Collaborative and has embraced that as one step to move forward. Gerry, would you agree with that?

**Dr O'CALLAGHAN** - Yes. We had a presentation yesterday and identified three main sorts of things that they wanted that they were going to recommend. One of those was the collaborative.

**CHAIR** - So you don't believe there's going to be any conflict at all between -

**Mrs COLEMAN** - Not about the collaborative, no.

**CHAIR** - Yes, right. I am asking you this because we were told at the start, 'You really want to proceed with this committee because the task force is going to come down with some recommendations maybe at some stage'.

**Dr O'CALLAGHAN** - I think the task force will provide a document, which I am sure they will be happy to provide to you if you ask for it. It will have a lot of information in it. We discussed it yesterday and the main thing that they've done which has been very helpful is they've provided an interface between donation and transplantation in a form, probably for the first time. I think there's a lot of very useful information that's come from the process, and a lot of their recommendations will be similar to a lot of the discussion here this morning. I think they've done that in a very rigorous, well-documented and open way. We were told there would be ongoing support for the collaborative will be not just sort of in-principle but actually effective.

**Mrs COLEMAN** - One of the issues from a jurisdictional point of view is that there's an initial \$23.4 million allocated over four years with recommendations to be made by the National Clinical Task Force as to priority items. There had been a notional allocation in May last year that is not generally public - and no reason for it not to be, but I knew about it - about certain amounts of money to go into certain things such as registries awareness, and so on. Because it is a Commonwealth budget allocation put on one side, of which 18 months of the four years is almost over - so two-and-a-half years to go - the

implications for the adoption of the recommendations that will emerge with ministers is a jurisdictional Commonwealth funding future.

**Ms HEE** - Just a comment, and that is I don't really think it matters which way it goes. I would recommend that you have something of your own in Tasmania, however you choose to structure it, but certainly with some local donor coordinators there. Secondly, we are quite happy to help at any step of the way if you are interested in all the coordinators coming across and seeing how we structured. If we can help in any way at all, just say the word.

**CHAIR** - Thanks very much.

**Mr HARRISS** - Do you have any comments on the interim report of the task force?

**Mrs COLEMAN** - I would like to provide some written comments, if I might. The reason for that is that I don't carry it around in my head and I didn't bring a copy with me. I noted that ministers accepted certain of the recommendations - awareness, a communications charter and a number of other things in work with the registries. I think there is some coming together of some good work that has been done by the task force, and I think there are questions around some of it as to the appropriateness, the funding, the practicality of some of it in the shorter term but I am sure that there are some longer-term aims that should be put away and incrementally worked on. Gerry, I do not know whether you would agree with it: not everything can happen on day one but there is some incremental progress that could be made, I think.

**Dr O'CALLAGHAN** - The task force has done a lot of work and there is a lot of reading there. I am not quite sure if you are going to sit down and read it all! It has been a very productive body which has been quite careful in the quality and the way it has done the work. I think what Marcia says is quite correct: I think it has had a longer-term aspirational goal for this sector of the country. I think it has done a good job with that. Whether or not the current political complexity will slow down achieving some of those goals remains to be seen. Probably the task force may have had a view that perhaps a stand-alone organisation would be better placed to pursue improving the sector in Australia rather than a committee which is made up of the sector and State governments dealing with whatever organisational methods you were to choose. But I have certainly sensed that that was more the direction that it was headed in. Obviously for the reasons that I as a clinician do not understand, I think there has been a softening of that. What Marcia is saying is that inevitably we will get back to that.

**CHAIR** - That was very helpful, thank you very much. Thanks for your time. I am sorry we took up so much of it, but it was very good. Thank you very much.

**THE WITNESSES WITHDREW.**

DISCUSSION WITH Mrs ROBYN HOOKES, DAVID HOOKES FOUNDATION.

**CHAIR** (Mr Wilkinson) - Good morning, Robyn. Thank you very much for giving us your time. As you probably realise, we're a Legislative Council select committee looking into organ donation and how we can improve the situation in Tasmania. We understand the tragic events with David. I met David a few times as I was involved with cricket in Tasmania. I realise what a good fellow he was. What we are asking you now is in relation to the terms of reference that you may have received from Sue with regard to the organ donation, just to see how we can improve it in Tasmania. What went through your mind when you were asked whether David would be able to donate his organs and what has occurred since?

**Mrs HOOKES** - It's a big journey. First and foremost, he made it very easy for me because he had discussed it for many years with us as a family. So from that point of view, at that point of sale, so to speak, my reaction was, 'Of course' because all of a sudden it gave me something that I could do for him. Because I knew how passionate he was, I couldn't have gone to bed at night without having done it once they had asked me. You would appreciate the shock and the tragic situation that the children and I were in, and your mind is not functioning normally. That didn't even occur to me because I've never seen anyone on life support. It was very difficult for me to come to terms with the difference between being in a coma and being brain dead. Initially it wasn't registering but if I think back to there and then, I had to ask them, 'Can you please explain that again?' In that 24-hour period I probably got them to explain that to me three or four times.

**CHAIR** - When were you first asked, Robyn? You would have heard the news and you and the children would have been extremely upset. A lot of things would have been going through your mind. You would have gone to the hospital. Were you then approached? If you were approached, by whom and how did they do it?

**Mrs HOOKES** - I went to the hospital on the Sunday night and it was probably a good hour - they were still cleaning him up and getting him set up. Nothing was mentioned about organ donation until probably after five o'clock the following day. That didn't occur to me because I kept thinking something was going to happen and once I saw him on the life support machine, he looked as though he was alive. I just thought, 'He's going to be okay in one way, shape or form' so I was not even thinking about the organ donation bit and they certainly did not bring it up with me at that time. But what I needed to know was the difference between a coma and brain death because they were not offering me the choice that he could stay on life support. I think I can remember saying to them, 'Why can't I take him home like that and have him on a machine?' I am being very candid here because I am not from a medical background. It sounded as though he was breathing because of the machine and his colour was really good so to all intents and purposes he just looked as though he was asleep.

**CHAIR** - Right.

**Mrs HOOKES** - The thing that they had to get through to me was that they were going to have to declare him dead and that was what I found difficult because you always hear of miracles happening when people have been in comas for many years and so on. That



was a difficulty for me and it was not until they were not giving me any other options and they were saying, 'We're going to announce to the world that he has died' that anyone approached me about it. The kids remember it as being someone from the hospital.

**CHAIR** - A doctor?

**Mrs HOOKES** - No, it was not a doctor. I think it was possibly the head of a welfare group.

**CHAIR** - Was it the organ donation coordinator?

**Mrs HOOKES** - That is my first memory. Violet was the first one who asked me so then we were with Violet virtually until she handed over to Bernie. At five o'clock there was a big press conference and they announced that he was dead. Then the kids and I went in with Violet and we started going through what we were going to donate and the whole procedure. It was scheduled that they would take his organs at, say, seven o'clock on the Tuesday morning but, because of delays and certain things, they did not take them until about half past twelve on the Tuesday afternoon.

The point with Violet was that I more or less wanted to hug her. It was a really beautiful moment for me and for the kids because we knew how he felt about it. It would probably be a different situation if you were unsure about what they thought but I was sure about David. From that point of view that was easy for us but I was still anxious and I was still concerned, especially once we started getting into what was going to be donated. My mind was racing. We had been through everything and then they started mentioning the skin and then they brought up, which I had forgotten until just recently, the fact that the Alfred take arteries - they took arteries from his leg -

**CHAIR** - Right.

**Mrs HOOKES** - and at that point it became a bit scary, but I was able to say, 'Hey, hang on a minute, I'm getting a bit scared now because what's he going to look like?' and so they did explain to me in relation to the tissue that it would just be a small section probably on the back of his shoulder that would be visible. Because I am not a medical person, I thought that there would be big holes in him everywhere and I was worried at that point as to how he was going to be and what he was going to have to go through. In fact, I can even remember saying to them, 'You will give him an anaesthetic, won't you?' Because he looked as though he was alive, I was worried that he was going to feel it or be in pain. So when they said no, that he would not have an anaesthetic - and I know that it is my ignorance - I worried that he was going to feel it. They said, 'He won't have an anaesthetic'. That is when they had to go back over the whole brain-dead thing because it was really hard seeing him look alive.

**CHAIR** - Am I right in saying, Robyn, that there were eight people who benefited or were there more?

**Mrs HOOKES** - They told me 10 and that is relative to the fact that they virtually took everything they could - bone tissue, corneas. All his organs were perfect, even his liver, which we laughed about at the time.

**CHAIR** - That would have been in good nick, wouldn't it?

**Mrs HOOKES** - The girls thought that he would be rapt with that. He would never have thought that his liver would be okay. I said that I always encouraged him to eat vegetables and at the end of day it did not matter because his organs were perfect anyway.

*Laughter.*

**Mrs HOOKES** - Further down the track, once I received his ashes, it all became very clear. But while you are with the body and while you are in that unbelievable state, which must be like a shell-shock, as my doctor explained it to me, you cannot see what the unbelievable result is going to be. The furthest thing really from your mind is helping other people. I do not mean that to be that I was feeling unkind but you are not even going there. You are not even in that mindset because you are hoping for a miracle, that he will sit up and say, 'I'm okay'. Apart from the fact that we were donating his organs, at the time there had been no publicity about the tissue and all the others that could go. So that was a new thing for me, the process, to agree to. But we are talking about nearly four years ago now.

While he was still on life support the pathologist and the coroner's office requested part of his spine so that was another thing that was going to be taken away as well. I was thinking, 'Oh my God, there's going to be nothing left of him' and so I was really focused on that. But because of everything that happened in relation to what the coroner had to hang onto, initially they said it would be six to eight weeks. I said, 'Don't bring him to the funeral director and don't bring me his ashes until everything can be put together', which is how it was handled. So it was quite a few months down the track before I received his ashes because of the fact they also had to come back to Adelaide and the coroner's bits were here and one thing and another.

**CHAIR** - Was there any tension at all, Robyn, with the coroner wanting to carry out some pathology reports, obviously, from the forensic pathologist in relation to the criminal case and the organ donation people?

**Mrs HOOKES** - No, because at that time - and I had to give permission to the pathologist for that - we had not even got to the organ donor stage. I remember even then when they were going to take it for the pathologist I still was not thinking about the ashes. It was not until I got further down the track and we realised where we were heading towards organ donation that I then remembered, 'Oh hang on a minute, they will take another bit for the coroner. Can I have everything put back together?' But can I say - and this is what I emphasise a lot - that when the ashes were brought home - and I was dreading getting them, thinking I would have a downward spiral day and all that sort of thing - I cannot tell you how much relief I felt when I saw the cylinder. My first reaction was 'Thank God we donated his organs because is that all I am going to get?' I felt what a waste it would have been if we had not done that.

I can say in all honesty that awareness in these cases means that you might need to go through that process yourself to really be comfortable with it. I know that that can't happen so I feel that part of my journey now is to relay as much as I can through that process so that people have a better understanding of how they might feel at the very end because I am aware of the number of families that do say no.

**CHAIR** - Robyn, did you see his body before it was cremated?

**Mrs HOOKES** - That was another really important thing to me. They had warned me that it potentially could be about seven or eight hours in theatre, which I was quite okay with, but I said that I needed to see him at the end so that I knew that he was okay. That was still in that mindset of my worrying about him all the time and worrying about whether he was going to feel it. I knew that he was dead - but the thought of that was not quite enough, and I had this feeling that -

**CHAIR** - Sure.

**Mrs HOOKES** - was worrying me and that is what we have to live with. When I saw him afterwards I pulled back the sheet so that I saw the very faint incision down his chest. He certainly did not have holes in his body and there was no skin ripped off. I did not turn him over, but I then was comfortable that they hadn't ripped all his skin off obviously they had taken a little bit from - probably his shoulder - and there were no visible signs around his eyes. To me he didn't look any different from my father and my grandmother, both of whom I saw after they had passed away. That is another thing that I reiterate when I discuss the matter with people. Then, of course, when he went he was dressed anyway.

**CHAIR** - So people who believe that the process is going to leave them scarred and with holes in them are mistaken - that just doesn't happen?

**Mrs HOOKES** - No. If anything I was surprised because the incision down his chest was as you would imagine for someone who had had heart surgery. Obviously he had a scar on his head but it didn't look angry - and, once again, I know nothing medically about anything - so they must drain the blood because it didn't even look bloody or raw or red. My memory of the incision on his chest was that it looked as if it was an old one. So my understanding is they drain the blood - I don't know - I don't know if any of you guys know?

**CHAIR** - No, I don't, I'm sorry.

**Mrs RATTRAY-WAGNER** - The medical expert, Robyn, is absent from our committee but I am sure that she would know.

**Mrs HOOKES** - Okay. So you are just as -

**Mrs RATTRAY-WAGNER** - Lay?

**Mrs HOOKES** - Yes.

**CHAIR** - We are just an upper House committee from the Tasmanian Parliament looking at organ donation in the hope that Tasmania can benefit from the recommendations that we will bring down.

**Mrs RATTRAY-WAGNER** - Robyn, can I just ask you a question about your children, if that is appropriate?

**Mrs HOOKES** - Sure, absolutely.

**Mrs RATTRAY-WAGNER** - Have you felt that being able to follow David's wishes to be an organ donor has helped the children to come to terms with what happened to their dad?

**Mrs HOOKES** - No, there are two separate areas there. They both had to endure the court trial, the manslaughter charge and not getting the result that we should have, and all those sorts of things. The one positive thing for all of us has been the organ donation side of it. I wouldn't say that the organ donation has helped them in any way with what they've been subjected to publicly and in the criminal justice system. But they know and can remember all those conversations we had around the dinner table when they were early teenagers. They remembered so vividly how positive he was. Even in the early days - and my children are 32 and 29 now, so it was a long time ago - he first started talking about it. He was so up with what was going on in the world and he felt strongly that we should have an opt-out system here. I don't even try to go there with that because I imagine that would never happen. He knew a lot and probably because of his career, having travelled a lot internationally with cricket, you really do have your eyes opened about a lot of thing. Because of the type of person he was - and if he said it once he said a hundred times 'What do you need your organ for when you're dead?' - he had absolutely no fear or anxiety about it whatsoever. I guess that is what helped us, and it certainly helped the children. Their approach to it is what I envisage and hope for the next generation, that it is part of *(inaudible)*

**Mrs RATTRAY-WAGNER** - Thanks for sharing that, Robyn. I know it must be difficult.

**CHAIR** - So the biggest message, Robyn, to get across to people is that you have to talk it over with your family?

**Mrs HOOKES** - Absolutely. I am very aware that there was a case where a family knew that the husband wanted to be an organ donor. He was the one who had died and the wife wanted to go ahead with his wishes but because the daughter was at a tricky age - I think she was about 12 - she was absolutely beside herself that that would happen to her father and she didn't want it to happen. Then the wife was in a dilemma as to how she could carry out her dead husband's wishes and deal with her daughter, who was still alive and living under her roof. You can understand why she said no. In every family you have to somehow pull yourself together and go along with what has happened. In our case, if my kids had been anti organ donation or were horrified by it or scared or hysterical about it, I probably would have had a tough time to make this go ahead. I do not know what the aspect is, but that child was so uncomfortable with it because they hadn't had a discussion in the family or they hadn't talked enough about it. I'll probably never know what the answer to that is but it is certainly something that must happen because from my understanding, from the last time I did something with Professor Graeme Noye, that of those that they know want to be donors, 54 per cent of the families say no. I find that staggering.

**CHAIR** - Was David registered?

**Mrs HOOKES** - David had ticked the box probably about 10 years ago - whenever the last time was that he renewed his licence in South Australia. But I also realise now that if you just tick the box, it just does not work. We had our David Hookes Foundation annual cricket match in the Barossa Valley on Friday and Wayne Holdsworth was playing for New South Wales and he and a few of the others said, 'I've ticked the box; I'm a donor'. I said, 'Well, you've really got to go back and do it again. Even those that are registered with intent on the pink card have to go back again'. Those that already have the pink card are so keen to do it properly that, once they know the requirements, they will probably go and redo it so that they get their green card of consent. But the ones that tick the box and walk around and say, 'I'm a donor' could probably be given a bit of a kick up the bum to get them registered correctly.

I know it is not their fault because, from a national point of view, it is not very clear. Every State is slightly different - not that there is that much to do; it is not about handing over money, it is just one of those things that you have to get around to, isn't it?

**CHAIR** - Yes, I understand that. There are some vital aspects: one is talking with the family; two is the registration; and then the third - and everybody hopes the event does not arise but with a few it unfortunately does arise - is the way the question is put to you, I suppose.

**Mrs HOOKES** - Meaning at the point?

**CHAIR** - Yes, when the medical fraternity ask you.

**Mrs HOOKES** - I think really at the end of the day, my experience is that the crucial thing at the top of the list has got to be discussion because it is the people who are left behind who have to deal with it. They have to put their head on their pillow and be comfortable with it. What makes it easier from that point of view is having had the discussion and knowing exactly how David felt about it. In my case, if I felt that I could not be a donor myself and did not want to be a donor, I still would not have had an issue in going ahead with David because I had his permission; he wanted me to do it.

We were not aware that we needed to be registered. We had all ticked the box, but we did not know because none of us really want to worry about death, do we?

**CHAIR** - That is right.

**Mrs HOOKES** - So it was not until now that I am so aware and of course the law of registering has changed since 1 July 2005, as you would well know. But that is something that I try to bring up. Even if I am talking to a couple of hundred people and I actually show them the card they will say, 'Oh, we've only got a pink card'. Because the tendency is to ignore it when all is well, you do not always take it on board, but I still have people who, after all this time, say to me, 'I'm a donor, I've ticked the box' and I just think, 'Oh my God, have they really registered?'

**CHAIR** - What about now? Does LifeGift keep getting in touch with you? I suppose because of your activities you would be in fairly constant contact with them but you would still have some down moments. Do they assist you with some counselling or whatever it might be?

**Mrs HOOKES** - Certainly initially and I must admit that both Bernie and Violet were just like my angels. One thing that you probably should know that was of enormous comfort to both myself and my daughter was the fact that Bernie said was going to be with David through the entire operation. My daughter and I both had the same reaction: 'What if you need to go to the toilet?' and Bernie said, 'No, I won't leave him'. They did talk about how he would be treated and that was also very important. Bernie said that she would not leave him and that was like a gift - that he would not have to be on his own. Even though we could not be there and we would not want to be there, she was really replacing us and I would see her at the door when I saw him again eight hours later.

**CHAIR** - What about now, four years down the track, do you need any assistance or do you believe people would need any assistance and is that forthcoming if necessary?

**Mrs HOOKES** - I am sure if I needed to and I contacted them, they would be there whatever. Certainly in the first six to 12 months I had many conversations with the girls there and they were wonderful. But what I understand about grieving and tragedy now is that you have to do it yourself and that is the hardest thing to get your head around. For all that they can say to you and support you, the easiest thing to do would be to curl up in a ball and not get out of bed. But the hardest thing is to tell yourself that you have to get on with every day, and nobody can do that for you. But certainly from the consultations that I have had with them, I did feel a little better in the sense that you do because there is someone who can listen and try to say those words that help you a little bit. You know that you could pick up the phone or go and see them. But we looked for all sorts of counselling and I was under a psychiatrist because I needed -

**CHAIR** - Some assistance?

**Mrs HOOKES** - Yes.

**CHAIR** - The circumstances surrounding the death probably traumatised you even more, didn't they?

**Mrs HOOKES** - Absolutely. Initially we had to go through the preliminary hearing, which ran for about three weeks and which was in the November after his death. Then the following year we had to steel ourselves to be ready for the trial, which went for a month. You had something to work towards so you knew that you had to be well, and probably that helped me. Initially they give you a whole lot of stuff to help you get through the day. I felt that I wanted to be off that so that I would be clear in my head for the trial, and I was able to do that. But I understand that not everyone is the same. Certainly whatever counselling is available, I would say everyone is entitled to it no matter how well they feel and that they probably need to have it.

**CHAIR** - Robyn, you have said that you go to Rotary clubs and other charitable groups and educate them in the process of organ donation. Do you believe there is enough done with education on organ donation?

**Mrs HOOKES** - No, I do not.

**CHAIR** - What should be done, in your view?

**Mrs HOOKES** - I think it's hands-on. I am only one person and there are lots of people who get out there and talk to groups. With the campaign to promote consent, the Government put a leaflet in everyone's house at that time. When it came to my house, I just thought that it was the kind of thing that I throw out with everything else that gets put in letterbox. It was not enough to grab me and make me want to do it. I do not have all the answers. I feel very strongly about talking to groups and that you need to get questions asked and then you get answers given. Most of those people will walk away and will either register on the night - sometimes that happens - or they will show me that they're already registered. They may ask me a question that is relative to someone they know who is not registered, whether it is due to illness or because they think they are too old or for whatever reason. I think that that then snowballs. If you talk to 200 people and they go home and talk to their family or to their extended family and friends, that then bubbles over and if those 200 people spoke to, conservatively, two other people or 10 other people, you are talking a lot of people. I think that goes with anything in relation to learning and people. People go into schools and talk about cigarettes, drugs and all those things. This could be part of our community in a sense and everyone could be incredibly aware of it from a young age and there wouldn't be the fear of it, but how you do that I don't know.

I know there are plenty of transplant recipient people who talk about what happened and how it improved their life. I have done a lot of functions with those people.

**CHAIR** - Have you heard from any of the recipients of David's organs?

**Mrs HOOKES** - I had several letters in relation to different organs in the first six months. I don't know who those people are and they don't know whose organs they received. I think in our case it is probably better that it is left anonymous.

**CHAIR** - We have had a bit of evidence about that. One opinion says, 'It's a bit like adoption. If the adopted child wants to track down the parent, if the parent and the child agrees, let it go ahead'. The other says, 'No, it shouldn't proceed'. It seems to be the same with organ donation. Your view would be, 'No, there's no real benefit in knowing who the recipients were'?

**Mrs HOOKES** - I don't need to know. On the strength of the letters I received, I have a pretty good picture. LifeGift sent me a letter and they asked me if I wanted to receive that letter. That would say basically the sexes and the approximate ages of where they went and it would all be itemised, which it was. I said to them, 'I don't want to be home on my own and receive a letter like that'. They directed it to my daughter, who is a midwife and nurse, and she did not have a problem with it. When they started coming, and then subsequent to that, a description of where everything went, I didn't read them or want to look at them for probably 12 months. I wasn't ready for that. Now, if I reflect, it is an emotional experience but it is a positive one. Now I am able to look at the ages and sexes of those people and say, 'My God, all these lives have been saved or dramatically improved'. That is something to rejoice in for the loss of his life.

**CHAIR** - That is correct. I should have mentioned to you at the start, Robyn, if there is anything you don't wish to have quoted in the report, please let me know and we can put that in camera.

**Mrs HOOKES** - I don't think I've said anything that can't be on the record.

**CHAIR** - No, I don't think so, but I just wanted to give you that choice. Thank you very much for giving up your time, Robyn.

**THE WITNESS WITHDREW.**



**DISCUSSION WITH MS SUE IRELAND MANAGER, BLOOD, ORGAN AND TISSUE PROGRAMS, SOUTH AUSTRALIAN HEALTH DEPARTMENT**

**CHAIR** - Sue, thanks very much for coming along today to give evidence and giving us your time. Anything you don't want said publicly, please let us know and it can be heard in camera. I understand you received a copy of our terms of reference on organ donation. We are well down the track of taking evidence, and there has been some good evidence. We are endeavouring to improve the situation in Tasmania; we have a good uptake of intentions by way of licences, but now they say it's not enough to just tick the box on the licence form, you have to sign the appropriate form.

About 20 000-odd have signed the appropriate form, and another 150 000-odd have ticked the box on the licence renewal form, so there's a problem there in relation to uptake from the licence into the forms. That is one of the areas I think we have to look at, together with the need for a coordinator within Tasmania. On the evidence it would seem that that is an important matter to be taken into account. So there are a couple of interesting things we can do in Tasmania.

However, we understand that South Australia is doing it better than anybody else, so we thought we would come to South Australia and have a chat to you and try to pick your brains.

**Ms IRELAND** - Do you want me to address the terms of reference as best I can, or are you happy to question me?

**CHAIR** - Whatever you feel most comfortable with.

**Ms IRELAND** - Should I describe my role?

**CHAIR** - Yes, please.

**Ms IRELAND** - Okay. There is an intergovernmental committee on organ and tissue donation where each of the departments of Health from the States and Territories meet. I represent South Australia on that committee, and that committee reports through AHMAC to health ministers through what is called CTEC, as you'd be aware. I understand that committee - and I would have to clarify that with the secretariat - has been in operation for about three years. I have been representing South Australian for approximately two. They have been attempting to address a lot of these same issues about the poor uptake of the AODR. I am sure you are aware of a lot of the national work that is underway at the moment?

**CHAIR** - We are aware that it is being undertaken but that is as far as it goes.

**Ms IRELAND** - Are you aware of the work of the National Clinical Task Force? Some of the people you have spoken to, such as Gerry for example, are the backbone of that organisation.

**CHAIR** - Yes.

**Ms IRELAND** - These have been telling times, but I think the question about the role of the AODR, the organ donor register, is a really important one. I will give you a general response as best I can, representing the Department of Health's views.

South Australia has, of course, maintained its link with the RTA. South Australia is one of the few States that has maintained the link - this is probably duplicating what Kathy Hee has already told you this morning. We have maintained the link with the RTA, mainly because we did not act rapidly enough to stop that link. So the RTA's information - what I call 'intent information' - is conveyed on to the AODR. I do not think New South Wales has that linkage, but you would need to confirm that with them. My understanding is that New South Wales does collect the information but it does not speak to the AODR in the same way. I think that we have put on hold a lot of our work with either re-establishing the RTAs around Australia or seeking other avenues of populating the AODR while we have been considering the access card and I think the future of that probably lies with the new Government.

**CHAIR** - Yes.

**Ms IRELAND** - So we will have to wait and see whether that progresses.

**CHAIR** - Have you heard whether the access card is going to be something that comes into play in the near future or is it out the window now?

**Ms IRELAND** - I cannot comment on that. I have an in-camera view! I think we will have to consider that a lot more over the next couple of months as to what we are going to do. We will be seeking some directions from the Department of Health and Ageing because they will be conveying the views of the new Federal minister.

I am quite pleased with that South Australia has kept its links with the RTA because there is a small but slow uptake on to the AODR. The merits of having a register sometimes have been questioned. The key point seems to be the process that happens in the intensive care unit, managing that consent process and also making sure there is a high level of awareness in the community. It is almost the icing on the cake having the AODR but now we have headed down that path we are quite committed to it policy-wise. Certainly it is not the be-all and end-all in terms of having donors.

**CHAIR** - That is what we have heard.

**Ms IRELAND** - Let me know if I am in conflict with any of my South Australian colleagues please.

*Laughter.*

**CHAIR** - You have all been together for a meeting beforehand.

*Laughter.*

**Ms IRELAND** - No, I do speak quite a bit with the manager of SAODA, Gerry O'Callaghan, who has taken quite a leadership role with South Australia through chairing the national

planning committee and the organ donor collaborative and he is also one of our key medical donor coordinators.

Much has been made of the role of the AODR and also about the 'intent versus consent' question. I guess pragmatically what I am hearing from the clinicians is that it does not really matter when you get to the situation whether it is an intent or consent because it is very challenging to move forward without having family support anyway, so that cannot be underestimated.

**CHAIR** - Sure. That would seem to me to be the biggest hurdle that has to be overcome - that is, discussing it with your family and making sure that your family is aware of whether you agree or do not agree.

**Ms IRELAND** - My understanding is that the level of confidence that the family can be approached with will vary depending on what is on the register and universally intensive care specialists are not finding out what is on the register before going to the family. So we do have process issues and certainly there are issues in terms of the clinical uptake and use of the AODR. My information is quite second-hand, if you like, but it is what I have been advised from the local sector.

In summary, although much has been made of it, I guess impact of the capacity for a person to register a legally valid consent is probably not as great as one would think when it comes to the actual process.

**Mrs RATTRAY-WAGNER** - In your view then, it is the communication with your family that is probably the most important aspect?

**Ms IRELAND** - I think probably having intent on the register is pretty much almost there. It is nice to have consent - was there any discussion this morning about the consent versus intent and the merits of that?

**CHAIR** - Not really. It was touched upon, but the major issue seems to be that if there is the intent then still that doesn't amount to what the medical fraternity would think is consent if the family doesn't agree. At all times it would seem that the family has to agree, or the ones who give the permission have to agree. If there is just the consent, as I understand it, of the intent on the form that is a good start.

**Ms IRELAND** - There's a pragmatic view as well from a clinical perspective.

**CHAIR** - The legalities could be questioned, I would say, because if the consent occurred 20 to 25 years ago, what is to say that it is current consent? I think that is always questionable.

**Ms IRELAND** - The other issue is what is an intent versus a consent anyway. This has been really muddy and has caused a lot of confusion in the community. In some respects we have adopted what might be the highest rather than the lowest common denominator. The lowest common denominator in terms of consent is that only one jurisdiction requires a signed, hard copy consent. So the process set up for the AODR and the hard copy forms to come back is really a requirement of possibly only one jurisdiction. In a lot of jurisdictions the requirement is not as great for it to be considered a lack of

objection or consent anyway. My understanding in South Australia in our legislation is that a lack of objection - and that is not required to be signed - having been demonstrated would be sufficient from the potential donor.

**CHAIR** - A lack of consent?

**Ms IRELAND** - A lack of objection. The formal consent process is more with the coordinating medical officer within the hospital who checks that the processes have been adhered to and there's no interest from the coroner in the case et cetera before proceeding. Again, it gets back to the fact that much has been made of the intent versus consent and the need for the hard copy forms. What we are calling 'intent' from a South Australian perspective probably fulfils the legal requirements for consent anyway.

**CHAIR** - The evidence we have heard shows that, if the doctor was aware of it when he went to speak with the people involved, then the questioning would be easier. In other words, I imagine he or she could say, 'I understand your husband' - or son, daughter or wife - 'has signed the register for donating his/her organs in relation to his/her wishes. We have to speak with you about it' - and then do it that way, which becomes a bit easier.

**Ms IRELAND** - I don't know if I have too much more to add. It is a very complex process. We have been struggling with this on a national basis, about the role of the AODR and the intent versus consent and whether it is important. What has probably been a failure in terms of the AODR gaining what the ideal was considered to be, the hard copy returned signed forms, it hasn't achieved that, but it still adds value just by the fact that someone through any process has gone to the bother of getting themselves on the register. However that might be viewed, there is some merit in that.

**CHAIR** - If it is just a signed consent, who is to say it is an informed consent? You might just sign it - that is where the argument lies.

**Ms IRELAND** - Exactly.

I can't comment on the adequacy of Tasmania's approach. I can only cover what South Australia is doing, if you like.

**CHAIR** - Sure.

**Ms IRELAND** - In South Australia, in the mid-1990s, well before I was involved, there was some contact made with Spain, and the South Australian Organ Donation Agency was set up. A similar process, a select committee, if you like, was set up through South Australia, which recommended that an agency be established. No doubt they were going through a similar level of soul-searching as Tasmania might be at the moment.

As a result of that, I believe an approach was made through AHMAC for South Australia to be the pilot and have the organ donation agency. I think it was established in about 1996 and over time some of the other jurisdictions have established agencies. I believe DonateWest was established as late as 2000, so certainly South Australia might have been one of the first.

There were links with Spain and the South Australian Health minister has re-established links with Spain just recently and visited the same director of the Spanish organisation ONT, Rafael Matesanz, in Madrid on a recent European tour. We are inviting him to come back to South Australia so that he can see how we've progressed, make suggestions and assess how far we have deviated from the vision, if you like.

Of course Spain is known for its relatively high donation rate, which probably has a number of things contributing to it - not just the national organisation. They've got national regional support and hospital-level support. It is probably not for me to expand on the reasons, but there are a number of contributing factors. That will be interesting and we are hoping to have him visit South Australia in the first half of next year.

**CHAIR** - I know we've been told that the reason Australia isn't as good as some other countries is that, firstly, the health system down here is very good, and secondly there are not the gunshot deaths.

**Ms IRELAND** - I'm not sure about the contribution that gun deaths make, but certainly with road trauma -

**CHAIR** - Yes, with the airbags, ABS brakes and so on.

**Ms IRELAND** - Yes, and the speed limits and the like, there has been a significant reduction.

**CHAIR** - Yes, helmets when you're riding bicycles, and things like that. One of the arguments is that that is why it's not as high as some other countries that don't have the same health matters.

**Ms IRELAND** - And certainly the promotion and regulation of safety at a government level.

**CHAIR** - Yes.

**Ms IRELAND** - I think it is anecdotal. We don't really know how much that contributes but certainly that's an observation that has been made.

Did Kathy and the others talk about the systems in place in South Australia?

**CHAIR** - They have touched upon it, but please continue if you are coming from a government view.

**Ms IRELAND** - South Australia has adopted a modified Spanish model. We don't know how far we have deviated from that since the mid-1990s, so I think it's quite timely that Dr Matesanz comes back and visits us. A key feature was the establishment of the organ donation agency, which provides State oversight. Of course that is not currently linking into any national body at the moment.

**CHAIR** - Is that a State body?

**Ms IRELAND** - It is a State body, the South Australian Organ Donation Agency.

**CHAIR** - How many in it and who pays for it?

**Ms IRELAND** - It is managed by Kathy Hee. I believe they've got a staff of about -

**CHAIR** - Four.

**Ms IRELAND** - I don't know if that includes Kathy, I'm not sure. There is a reasonable level of turnover with organ donor coordinators; I would think it would be quite a stressful kind of job. They have a small staff complement with some administrative staff. I can give you the details of the staffing profiles if you would like that.

I believe there has been a review of what has been available in some of the other fora, like the national task force, about what is occurring around Australia. So that is funded through the Department of Health. It did report directly to the Department of Health but we had a restructure about two to three years ago and it was subsequently moved out into a health region - we have several health regions in South Australia. It has the same reporting structure as a major hospital might have. So it reports to a health region but services the entire State. That is funded as a grant from the Department of Health out to the region, which then manages them and makes sure they are appropriately staffed and the like. We are looking at reinstating a position of medical director of the organ donation agency, through a number of staff changes. The position fell vacant. It has been quite an oversight that we have not replaced the senior medico - that is, the Medical Director of the Organ Donation Agency.

**Mr HARRISS** - Has there been any detriment to the program because of that position being vacant for a period of time?

**Ms IRELAND** - I cannot comment and it is really hard to ascertain. In South Australia, because of its size there is variability in donation numbers anyway, so it is hard to ascertain whether a year is high or low due to any single factor.

The Organ Donation Agency is funded by the department. At present there are also four medical donor coordinators - clinicians that are based in intensive care units in our four hospitals. We will probably be reviewing that. South Australia has a health care plan which will mean increased activity in some ICUs. The Queen Elizabeth Hospital ICU will probably become a high dependency unit rather than a formal ICU. So we will have to review that in light of our health care plan and where things are moving in the next five to 10 years.

A medical donor coordinator's unit is paid a small stipend or honorarium for their work. That is generally put towards staff development and awareness-raising within the intensive care unit. It really is quite a phenomenal amount of money at the moment. I think it has been indexed-up recently and is in the order of \$100 000 shared between the four hospitals. So you are looking at \$30 000 to \$35 000 for a major teaching hospital for that small level of funding that helps them to send people to conferences and courses and the like. It does mean that one clinician in the intensive care unit is given that specific little portfolio of being responsible for organ donation. They also represent that hospital when we have meetings of our peak advisory group in South Australia, which is on Saturday. Did Kathy mention that?

**CHAIR** - No.

**Ms IRELAND** - It is our State peak body. The South Australian Transplantation Organ Donation Advisory Council is attended by people who are interested, our medical donor coordinators, SAODA, and the clinicians involved in transplant and in the retrieval process. They are meeting on a regular basis, generally four times a year.

**CHAIR** - Is that mainly about audit, going through the hospitals as a result of the coordinators saying, 'Why did we miss this one or that one?'

**Ms IRELAND** - That micro-analysis occurs with SAODA, but generally they are interested in how things are progressing in terms of consent rates and conversion rates. Certainly statistics are discussed. There are no KPIs, if you like, used at the moment or set -

**CHAIR** - Should there be?

**Ms IRELAND** - It is one of the things that will be considered. That sort of more structured reporting is part of the Spanish model. In any area where you actually have certain outcomes and goals you want to achieve, it is one of the things that you would have to look at. It is quite soft reporting, if you like, quite a collegiate atmosphere.

**CHAIR** - Right.

**Ms IRELAND** - So it is not a formal reporting process for the department. My role is to liaise between the committee and the department. They certainly discuss clinical protocols. There has been consideration of donation after cardiac death, and because that is a more sensitive area it certainly requires a fair bit of input. They will discuss political protocols, progress, activity levels, issues, and liaison issues that might arise between, say, SAODA and the hospitals. We also have tissue-bank people on there as well. We have an eye bank and a tissue bank. The tissue bank is predominantly for bone but they do handle skin from interstate.

The peak advisory group has predominantly clinical people. I am one of the few non-clinical people that attends. We also have an Australians Donate board member that attends. If there are policy, legislative or other areas that we need to explore, I can help facilitate that if they want some advice from outside the committee. Funding of course is always discussed.

*Laughter.*

**CHAIR** - What are your personal views for Tasmania?

**Ms IRELAND** - I can only provide my observations as a departmental officer at national fora and from my local engagement with the sector.

**CHAIR** - You believe that organ donation coordinators are worthwhile?

**Ms IRELAND** - Yes, it does seem to be working. There is probably some further work that we could do in terms of formalising the role. I am not sure they have job and personnel specs and things like that. I do not think it has been formalised in that way. Maybe there

is a bit more work we can do on that. I would be very interested to see what happens after Rafael Matesanz's visit from Spain. That will only happen after I have finished organising the arrangements. I will be interested to hear more about how it actually works in Europe because I think that model has actually been adopted in some other countries as well. I would be interested in how we could sharpen up our model a little bit more and make that work even better.

You need to have a consistent clinical person you can go to, so you know who to contact. If there are issues then I know whom I can go to at the Royal Adelaide or the Flinders Medical Centre. Having a consistent liaison person for the hospital seems to be of some benefit and it certainly needs to be someone who embraces organ donation. Our challenge is to make organ donation part of the normal business of an intensive care unit.

**CHAIR** - Yes. You said 'consistent liaison' with a person at the hospital. I am just trying to think how that works. You have the organ donation coordinator in the hospital?

**Ms IRELAND** - From SAODA?

**CHAIR** - Yes.

**Ms IRELAND** - My understanding is that they spend about two days a week on site at the hospital.

**CHAIR** - So if you wanted to make contact with somebody in relation to organ donation, you would contact that coordinator?

**Ms IRELAND** - I don't have reason to contact them on a clinical basis; it would more be a case of if, from a departmental perspective, I wanted to make an inquiry about something that we might have heard has happened or there are questions raised about how some process might be working. It all operates without me quite well. I am sitting back as an administrator in the department and if something came up at SATODAC then I could have a choice of going to SAODA, if I thought it was primarily an issue for them, if I wanted to explore how the business process worked - for example, how can we improve the way that the tissue bank operates. There are issues that come up at SATODAC and why is it that the tissue bank may or may not be optimising its opportunities for donors. I could go to SAODA and get their perspective. I might then go to the hospital and contact their medical donor coordinator and find out from their perspective. I might not necessarily get the same comments, but certainly it gives me someone at the Royal Adelaide that I can ask, 'What's the process at the Royal Adelaide for dealing with coronial cases and organ donation?' - and I can find out what their process is. That is of benefit to me because the director of intensive care is going to have many conflicting priorities.

**CHAIR** - Here you have the organ donation coordinator and the medical donor coordinator. Do you need the two?

**Ms IRELAND** - They probably add something different. As I said, we probably need to flesh it out and find out exactly what we would like them to do and whether they are doing it -



**CHAIR** - So there's no job description with either of them?

**Ms IRELAND** - There are certainly job descriptions for Kathy Hee's staff. My understanding is that the medical donor coordinators look after the clinical education, identifying donors and a whole raft of other issues in the intensive care unit, whereas SAODA is quite actively involved in the process - and even the national liaison - of the offer of organs and the like. They do a lot of liaison with transplant units and the national system that kicks into play if, for example, organs are not going to be used in South Australia. We don't use hearts and lungs in South Australia because we only have liver and kidney transplants.

**CHAIR** - What do you do with your hearts and lungs?

**Ms IRELAND** - They go interstate, to Melbourne generally, I believe. There are arrangements and there is some sort of allocation roster, the magic of which I'm not aware.

**CHAIR** - Tasmanians used to fly across to Adelaide years ago if they wanted -

**Ms IRELAND** - For kidneys?

**CHAIR** - No, for hearts - if they wanted bypasses.

**Ms IRELAND** - Oh, bypass, yes. But, no, we don't do heart transplants. There are some organs there will always be offered interstate and there are other ones that will be offered interstate only when they've gone through their routine process, which generally means an offer locally for kidneys, for example.

SAODA manages that. The intensive care unit is not going to be interested in ringing around Australia and going through that process. That's not their business; their business is to look after the person that is pronounced brain dead and the family. They're not involved in this liaison role that SAODA is.

I have covered SATODAC, which is the peak body, and the medical donor coordinators - a small stipend is paid to their units, not to them directly. I think probably some level of credibility is afforded them for their leadership role in the intensive care units and SAODR. So we have several layers that work together.

**CHAIR** - Have you done any work on the net worth of South Australia having an organ donor rate better than anywhere else in Australia?

**Ms IRELAND** - No, I have not done that work. I believe some work has been done previously about the cost of dialysis compared with kidney donation in particular.

**CHAIR** - We've heard about that.

**Ms IRELAND** - I think Transplant Australia might have done it and Kidney Health Australia has done some work on that.

**Mr HARRISS** - AD have done some as well but Kidney Health have certainly some stats on their web site, so Marcia told us this morning.

**Ms IRELAND** - I am no more informed than that.

The other thing that I guess has been a bit challenging is private hospitals. I did some work in South Australia - I apologise because I do not have the stats in front of me - and I am happy to provide some information to you outside of this due process, if I can be of any assistance.

**CHAIR** - Thank you.

**Ms IRELAND** - We have had a couple of occasions with private hospitals where organ donation has usually been raised by the family and they have subsequently progressed to donation - this is in an intensive care unit and brain death being pronounced - and we have identified that there has been a lack of clarity about funding. So in response to that, the Department of Health has organised an offer of funding to private hospitals of \$5 000 per case for organ donation. They have to provide information to justify it to the organ donation agency - an invoice, if you like, for the cost of intensive care time, the use of their theatres and any private clinicians such as people who are familiar with the theatre who need to be there, the anaesthetists and theatre nursing staff. I have made it very clear that is not payment for an organ, it is not payment for a donor, it is payment for any of their costs to their institution for being involved in the process. This is because it was perceived as being a barrier and certainly a high level of discomfort, if you like, in having a family that it is eager for their recently-deceased member to be a donor and our not having the policy and funding arrangements in place to support that.

I would have to confirm the figures, but I recall that an additional five to six maximum donors per annum were anticipated from the private sector. We only have possibly about one per annum in South Australia at the moment. That was just using very basic hospital information based on the deaths in hospital that have had some time in intensive care. They are very basic statistics to try to work out the likely hospital increase in donation if we were to include private sector. There is not a great appetite I would say for pursuing and promoting organ donations because we do not have the strong linkages between the Department of Health-public sector systems and the private sector. But certainly it would be very sad if you could not fulfil a deceased's wishes. If they have obviously been on the register and their family wants to donate, I think it is a bit sad if we cannot make that happen for them.

**Mr HARRISS** - So it is not a major national drain or anything like that?

**Ms IRELAND** - It is not enough to be a huge motivator for organ donation but it also means that we do not end up with a perceived financial barrier.

**Mr HARRISS** - But the issue really rests with some national initiative, doesn't it, if there is to be some attention in private hospitals as opposed to the public hospitals?

**Ms IRELAND** - That's right. I have done some work with Medicare and liaised with Medicare about what there is payment for and there was a very clear message that in fact organ donation was the domain of the public sector. There are no funding arrangements

that I am aware of through the MBS, Medicare or private insurers. Once a person dies in a private hospital, my understanding is that the capacity for billing relating to that case finishes. So that is quite challenging if you have a private hospital with someone in an intensive care unit for another day or so while all of this is being fully explored. It is an unnecessary impost on them.

**CHAIR** - What about the policy you have in South Australia of a family wanting to donate a kidney from their very ill child to the person down the road or to a friend?

**Ms IRELAND** - Are you talking about directed donation?

**CHAIR** - Yes.

**Ms IRELAND** - We have not had a clear policy. I think that is probably one of the things we need to address on a national basis.

**Ms IRELAND** - I was just mindful that there are some controversial issues on directed donation that are still up for discussion and agreement on a national basis.

**CHAIR** - If you were starting afresh, which Tasmania is not, what would you be telling Tasmania to do?

**Ms IRELAND** - It's good to have some people on the ground, if you like, in the hospital. They need to be a medical person and a coordinator, possibly with a nursing background. It is important to have clinical leadership. Having a clinical leader designated at the hospital intensive care - an intensivist - is probably a priority. Then you need someone who can actually make it work in a seamless way so you can interact with the other agencies around Australia in as seamless a manner as possible. I think it is really important.

Also, the organ donation agency does the local profile work in terms of community profile. They are in the Mall when there is an organ donor awareness week and all of that. They look for opportunities for awareness-raising. I don't know how many intensive care units you have in Tassie. Hobart and Launceston?

**CHAIR** - And Burnie. Is it still there in the Mersey?

**Mrs RATTRAY-WAGNER** - It is, because Mr Abbott made sure it was going to stay there.

**CHAIR** - Yes. Calvary, too, has an intensive care unit - a private hospital.

**Ms IRELAND** - Having some strategically placed clinical leadership roles doesn't mean every single ICU has to have one. You need to have someone that's going to engage, even on the national collaboration that has been occurring now. The learning from that needs to be brought back to the unit, so it's good having someone that can focus on that. At the national collaborative conference that was on yesterday, we had three of the medical donor coordinators in South Australia.

It is difficult to know whether you appoint someone or -

**CHAIR** - Persuade somebody who's already there?

**Ms IRELAND** - Yes. It's good to have someone who has an interest, who is interested in taking it on. Having that local agency support is important. I am aware that you are supported through LifeGift in Victoria.

**CHAIR** - Yes

**Ms IRELAND** - Looking at just one of them in isolation is problematic because they actually speak to different professional groups and they have different roles and functions. The clinician of course at the hospital would find it more challenging if they were expected to be involved in any of this liaison work. You're using LifeGift in Victoria, but I guess the question is whether that is ideal for Tasmania. Can you think of anyone physically located in Tassie from LifeGift?

**CHAIR** - No. If they need a coordinator, the coordinator comes across from LifeGift and speaks with the necessary people. One of the important things they've said to us is that we need an organ donation coordinator.

**Ms IRELAND** - I would probably concur with that. Even if they operated as a hub-and-spoke model out of LifeGift, then I think that could work as well. Northern Territory I think has one organ donor coordinator, and they do liaise quite a bit with SAODA. That model might be worthwhile looking at for the relationship between Tasmania and LifeGift.

Do you want to have an organisation with its own Tasmania profile and branding or want to operate as part of LifeGift? Will it mean more for Tasmanians in terms of local ownership if they have a local brand?

**CHAIR** - So Northern Territory are fairly well linked with SAODA?

**Ms IRELAND** - They have their own name. It is not the South Australian Organ Donation Agency up there; they have their own brand. They liaise quite a bit with SAODA as well.

**Mr HARRISS** - Sue, you have a system that operates very successfully here and is lauded, quite appropriately, but that is with SAODA in effect coordinating it all. However, you're suggesting to us that we develop some links with LifeGift.

**Ms IRELAND** - That's one of the options. You would have to look at the relative merits of the level of independence that you would want for Tasmania. If you just had one or two coordinators in Tasmania, what kind of government structure do you want? Do you want them reporting to LifeGift or do you want them to be relatively independent and just liaise with LifeGift as required to make sure that they're up to date in terms of education. They can have a collaboration with LifeGift rather than a direct reporting relationship. I think that's something you'd have to look into.

**Mr HARRISS** - Do you have a collaboration with LifeGift?

**Ms IRELAND** - That would occur through SAODA. All the State-based agencies around Australia get together. They have their own working group and that occurs through the organ donation agency, not through South Australia directly. Kathy Hee, for example, has a relationship with all of the managers of the other agencies around Australia. You would have to consider the relative merits of whether Tasmania would like to have a seat at the table as an agency in its own right or whether it would like to put some people on the ground and operate through LifeGift. I think probably having a seat at the table might be something worthwhile. If you want to look at other jurisdictions, the ACT has its own coordinator but I think it goes through LifeGift. I think there are a couple of different models in place. You are a lot bigger than ACT; you are probably large enough to have an agency of your own, I would think. The ACT, I believe, is under the banner of LifeGift. My understanding is that the ACT has its own coordinator but is part of one of the broader eastern seaboard agencies, so I don't believe it has its own brand. The Northern Territory has its own name but has a collaboration. I think possibly the Northern Territory model might suit you better.

**CHAIR** - Do you know David Boadle from Tasmania?

**Ms IRELAND** - Yes, I do. He was a colleague on the ITC intergovernmental committee.

**CHAIR** - Could David be the medical coordinator down there?

**Ms IRELAND** - I don't know David's background, but it doesn't need to be one full-time person. It is only a fraction of someone's role. Their key role here in Adelaide is as an intensive care specialist. It is just one of the little portfolios. People in any sort of work group have portfolios of different responsibilities. Someone from the group of intensive care specialists will take that on. That role needs someone who can relate to their colleagues as professionals, so they should ideally be in the intensive care ward, not a medical administrator sitting elsewhere.

**CHAIR** - Whom do they report to?

**Ms IRELAND** - In their daily role they would be reporting to the director of the intensive care unit about matters of intensive care, but certainly they come along to SATODAC in their own right as the leader from that hospital. In terms of government, they report to the director because they are employed by the intensive care unit. In terms of their clinical practice, if there's anything they should be doing they would have, for example, to float it as, 'I hear that Flinders Medical Centre is doing this. Are we interested in doing that here?'. They would have to discuss it with their colleagues. If they're going to take that forward they need to be pretty tuned in to intensive care practice.

**CHAIR** - If LifeGift was still the overarching body, they would report to LifeGift?

**Ms IRELAND** - The medical donor coordinator does not report to the organ donation agency. They collaborate with them and liaise with them but, as a senior medical consultant within the intensive care unit, they will not be reporting to the organ donation agency. They are not answerable to them in terms of governance.

**CHAIR** - Okay, if somebody says, 'Look, you've missed about three or four potential donors. There's been an obvious mistake made', where does the buck stop?

**Ms IRELAND** - SATODAC cooperates in quite a collegiate style. What the reasons might be would be raised. SAODA might help investigate why they have missed them.

**Ms IRELAND** - The quality of the requesting is important. That concerns the clinician in the intensive care unit, so there needs to be some interest at that level.

We are having some discussion, and I think probably more discussion is coming up, about designated requests, particularly where it is a very uncommon event. That is challenging. If you have an intensive care unit where it is an uncommon event to have a donor, how do you maintain that level of expertise and comfort that people have in the process so that they know what they are doing? This is from a clinician's perspective. Your newly appointed medical donor coordinator has to get some expertise and be comfortable with asking families; how can you progress that? You do not want to have everyone in the ICU having a go; it is not something that you have a go at.

**CHAIR** - Sure.

**Ms IRELAND** - So that is training as well.

**CHAIR** - Even though they do not have designated askers here it would seem that is the way it works. Gerry is obviously very good at doing it; because of his expertise and his experience he makes the family feel comfortable in the knowledge that he knows what he is doing. He is experienced and he gets more agreements than others because he is experienced in the field. He was saying he gets the younger ones along as well so they can become the Gerrys in years to come.

**Ms IRELAND** - They do need to have the opportunity to share and give others the experience, but that needs to be balanced with maintaining a reasonable success rate.

**CHAIR** - Sure.

**Ms IRELAND** - There is a reasonable level of training available under the ADAPT process.

These are quite challenging times. There is a lot of policy discussion and we are outdoing ourselves with the number of committees and working parties on a national basis.

**CHAIR** - There is a report coming down in December?

**Ms IRELAND** - The task force recommendations, yes

**Mr HARRISS** - There has been some vision at the national departmental level, because of the things that are happening, but it needs to expand a bit. There needs to be more funding provided so that we can see a greater conversion from intention to consent.

**Ms IRELAND** - One of the big challenges has been fleshing out the role of the intensive care specialists. I guess they are somewhat conflicted. They do not want to be perceived to have any conflict of interest in caring for the dying in those last days and then moving over to requesting. So it can be quite challenging and I think that has been something that we are all very mindful of. I think it probably rests with the intensive care units as to how that is all managed.

**CHAIR** - Yes, and the culture that has obviously grown up in South Australia.

**Ms IRELAND** - It has carried on from Gerry's predecessor at Flinders. Flinders has probably one of the best donation rates throughout Australia and I think that has carried on with Gerry. We are very fortunate; Flinders Medical Centre has been a leading light and as a State they make us look good.

**CHAIR** - Thank you very much.

**THE WITNESS WITHDREW.**