(No. 15)

2008

Parliament of Tasmania

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

Members of the Committee

Ms *Ruth Forrest*
Mrs *Rattray-Wagner*
Mr *Paul Harriss*
Mr *Jim Wilkinson* (Chair)

Secretary: Mrs Sue McLeod

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Executive Summary

Australia is acknowledged as having a low rate of organ donation and Tasmania's organ donation performance, when measured in terms of donors per million of population, has fluctuated dramatically over the last five years. For this reason and due to the shortage in organ availability generally, this Committee was established to examine what could be done to increase the rate of donation in Tasmania and ensure that it remains at a reasonable level. Australia has over 1800 people on organ waiting lists and only 198 individuals donated their organs after death last year.

Initially, the Committee sought to examine the competing ideology of a system where all are presumed to consent unless they choose to opt-out. This system has received increased media coverage of late and is being investigated by other countries; however, the evidence presented to the Committee suggested that it would not be well received by Tasmanians. It was thought that a change to such a scheme would increase anxiety associated with organ donation without necessarily increasing the donation rate. The majority of medical professionals consulted believed that enforcing donation against the will of other family members would not be something that Australians would support or like to contemplate. Instead, it was suggested that the system should encourage a greater understanding of the current processes and how they effect individuals.

The manner in which organ donation is raised with relatives in hospitals can have a crucial impact on their decision whether or not to donate. Evidence presented to the Committee strongly supported the need for trained professionals to be located within hospitals in Tasmania to act as Organ Donor Coordinators, rather than relying on trained staff arriving from Victoria. It was also believed that greater education of all relevant medical professionals would increase the donation rate by providing them with a greater understanding of the issues involved with donation.

The key message that was derived from both the written submissions and verbal evidence was that education and discussion are the most important aspects. The Australian Organ Donor Register (AODR) allows individuals to register their consent to donation, however, ultimately it will be the next of kin who decide whether their loved one's organs are donated. Whilst legally there may be an argument that the consent of the deceased is binding, in practice, no medical professional would enforce such a decision against the wishes of a family member. For this reason, decisions to donate need to be discussed with family or loved ones prior to registering consent.

It was suggested that organ donation should become a normalised topic of conversation within families and that consistent advertising is needed to support this. The number of family members refusing to donate the organs of their relatives is far higher when the individual's wishes were not known. Consequently, more people need to discuss their wishes with their family and friends and register their consent to donation on the AODR.

Some criticism has been launched at the AODR due to the complexity involved in registering. This process should be facilitated through greater availability of forms and by increasing the means by which registration can occur, utilising the internet and other options.

A far higher percentage of people more readily accepted the concept of organ transplantation if it benefited a loved one. This was in contrast to the number of people willing to register as organ donors. All those on waiting lists are someone's loved ones and in need of the help of a stranger to save their lives.

Organ donation can have a dramatic impact on the lives of the seriously ill and may provide the only option for quality of life, or life itself. It is essential that the community fully understand the value and processes involved with organ donation.

Below are two personal experiences related in a publication from the Donor Tissue Bank of Victoria which demonstrate the value of such a gift:

> "Our 13 year old son, Nicholas, was badly burned while sleeping in a caravan on a school excursion. With burns to 86 per cent of his body, donated skin was used to dress his wounds, while his own skin was cultured for grafting. No words of thanks could adequately express our gratitude to those who made the decision to give, at such a difficult and traumatic time, so that our son survived and recovered against all odds to walk and run again."[1]
>
> "At 46 I am having my third chance at life. I have had two heart valve replacements. The first was required after suspected undiagnosed rheumatic fever. The second was needed two years later when the first valve malfunctioned due to an infection. The generosity of donor families has allowed me not only to escape premature death, but to lead a full and healthy life, free of drugs and frequent blood tests. My husband and three sons are as grateful to these courageous and selfless families as I am and we wouldn't hesitate to follow their fine example if anything ever happened to any of us."[2]

The Committee Members extend their sympathy and condolences to the family of Mr Rudie Sypkes and posthumously thank him for his contribution to raising awareness of the issues surrounding organ donation.

Parliament House, Hobart
11 June 2008

Jim Wilkinson MLC
<u>Chairman</u>

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[1] Donor Tissue Bank of Victoria brochure

[2] Ibid.

Recommendations

The Committee recommends that :

Chapter 2

1. The current 'opt in' system for registration of consent to donate be maintained.

2. More options be provided to allow for the registration of consent to donation on the Australian Organ Donor Register. Online registration should be accepted as a sole means of registration ending the requirement for follow up paperwork.

3. Registration processes for consent to donate encourage discussion with family members.

4. Registration processes for consent to donate include contact details for relevant additional information.

5. Universal registration not be adopted.

6. Greater community awareness of the process for legally registering consent be promoted through a national media campaign.

7. Those who have indicated their intent to donate on their drivers' licence, be contacted and provided with information regarding the validity of the consent, together with a valid donor registration form.

8. Over the next five years, all drivers' licence renewals include the current application form to register as an organ donor.

Chapter 3

9. The establishment of a procedure to routinely measure and report on key aspects of the organ donation system's performance in Tasmania, including a formal audit of deaths that occur when organ donation may have been possible, rates of request, consent and donor conversion rates.

10. (a) The appointment of one full time equivalent organ donor coordinator to facilitate the organ donation process within Tasmanian hospitals. Such role to –

- "provide a 24 hour on call service and coordinate all the tasks involved in the donation process;
- provide support to clinical staff and to the family of the potential donor;

- [be] responsible for ensuring that the legal, ethical, clinical and procedural requirements of the consent, referral and retrieval process are met;
- have close contact and cooperation with the donor family, donor hospital and the surgical retrieval teams;
- provide ongoing bereavement support and counselling to donor families over time;
- [be] responsible for the documentation of the many relevant protocols and procedures undertaken; and
- play a pivotal role in the education of health care professionals (eg. medical, nursing and allied health) regarding all aspects of brain death and the donation process."[3]

(b) The role of the Organ Donation Coordinator should also involve community education programs.

11. Intensive Care Unit staff be educated to consistently check the ADOR when a potential organ donor is receiving care in the unit.

12. Data related to the quantum of patients who die in Australia whilst awaiting organ transplantation be collected.

13. Tasmanian legislation relating to the definition of and time of death be reviewed to ensure consistency of interpretation.

14. Tasmanian and Commonwealth legislation be reviewed to facilitate altruistic or directed donation.

15. In cases of altruistic or directed donation, financial support be considered for loss of earnings during the time of incapacitation relating to surgery.

16. Tasmania reconsider participating in the National Organ Donation Collaborative.

Chapter 4

17. All healthcare professionals be made aware of the processes and procedures relating to organ donation.

18. Education programs be provided for all specialist nursing and medical professionals involved in providing care to potential donors and their families.

19. Organ donation and transplantation be included as an essential component of education and training of intensive care and emergency medicine medical specialists.

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[3] National Clinical Taskforce on Organ and Tissue Donation - Final Report: Think Nationally, Act Locally, January 2008, p 47

20. Consistent advertising campaigns and education programs be implemented, that :

(a) promote a greater understanding of organ donation in Australia;
(b) provide programs aimed at normalising organ donation and provide information that accurately reflects the incidence and circumstances in which organ donation may occur;
(c) encourage discussions relating to organ donation with other family members;
(d) are conducted regularly throughout the year with a public health promotion focus; and
(e) provide a point of contact for further information and discussion.

21. Appropriate support be provided to staff involved in any aspect of organ donation, acknowledging and recognising the possibility of a personal connection to the patient.

22. Appropriate support and funding for healthcare providers and services to ensure high quality end-of-life care, including the option to donate.

Introduction

Chapter 1

1.1 APPOINTMENT AND TERMS OF REFERENCE

On Tuesday, 5 June 2007 the Legislative Council resolved that a Select Committee be appointed with power to send for persons and papers, with leave to sit during any adjournment of the Council, and with leave to adjourn from place to place, and with leave to report from time to time, to inquire into and report upon —

(1) Whether the present systems established within –
  (a) Tasmania; and
  (b) Australia,

  that enable a person to register a legally, valid consent to become an organ donor are adequate;

(2) The adequacy of Tasmania's approach in identifying potential donors and facilitating the donation and procurement process;

(3) The impediments, if any, causing Tasmanians to have the lowest organ donor rates in the nation and the net worth to Tasmania of having an organ donor rate equal to the best in the nation;

(4) The impact that uncertainty amongst family members regarding an individual's donation wishes has on their decision to allow organ donation and whether there is a reluctance on the part of doctors and family to proceed with donation even when the wishes of the donor were known to favour donation;

(5) Whether there is a suitable education and promotion program in place to ensure the community appreciates the need for organ donation and understands the personal, social and financial benefits that donation and transplantation brings to the community; and

Any other matters incidental thereto.

The Committee comprised four Members of the Legislative Council – Ms Ruth Forrest, Mr Paul Harriss, Mrs Tania Rattray-Wagner and Mr Jim Wilkinson (Chairman).

1.2 THE REASON FOR ESTABLISHING THE COMMITTEE

The Committee was established because of concern regarding the large number of Australians currently on the organ transplant waiting list and in particular the perceived low donor rate in Tasmania. Mr *Wilkinson*, in moving for the establishment of the Committee, stated that:

> "… one in five of those on the waiting list will die before an organ becomes available and there are others who die without ever making it onto the list".[4]

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[4] Wilkinson, Hon J., Hansard, 5 June 2007, p. 88.

He went on to say :

> "… I have heard stories of untold sadness as loved ones on the transplant waiting list have lost their fight against time, waiting for a suitable organ donor to become available. I have heard stories of miracles also where transplant recipients have been given a second chance of life, often as they are at death's door. But most significantly I have heard stories of lives in limbo, stories of a day-by-day, hour-by-hour waiting game, where an individual could be expected to wait as long as four years for a kidney transplant. They wait for the phone call that advises them that another human's loss has been their saviour. Unfortunately, there is no guarantee that the phone calls will ever come".[5]
>
> "…The organ donation debate is full of unknowns. It is time to measure in real terms the degree of support for organ donation".[6]

It was for these reasons that the Committee was established and to investigate the impediments, if any, causing Tasmania to have the lowest organ donor rates in the nation.

1.3 PROCEEDINGS

The Committee called for evidence in advertisements placed in the three daily newspapers. In addition invitations were sent to key stakeholder groups and individuals.

Sixteen written submissions were received and verbal evidence given by twenty three witnesses in Tasmania and seven witnesses interstate.

The Committee met on fourteen occasions. The Minutes of such meetings are set out in Attachment 4.

The witnesses are listed in Attachment 1. Documents received into evidence are listed in Attachment 3.

1.2 ACKNOWLEDGEMENTS

The Committee acknowledges and thanks all those who contributed to this report and particularly those officers interstate who gave such valuable information to the Committee and co-operated with its task.

The Committee gives special thanks to the Clerk-Assistant, Mrs Sue McLeod and Research Assistant, Miss Emily Freeman, whose dedication and ability to assist the Committee in organising its tasks were invaluable.

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[5] Wilkinson, op. cit.

[6] Ibid., p. 89.

Present Systems Chapter 2

TERM OF REFERENCE (1)

Whether the present systems established within –
(a) Tasmania; and
(b) Australia,
that enable a person to register a legally, valid consent to become an organ donor are adequate.

Australia currently operates an "opt-in" system of organ donation. This means that to enable organ donation to proceed, each individual, or their next of kin after death, must have registered their consent. The present system for registration of consent to donation throughout Australia is via the Australian Organ Donor Register (AODR). This register was established in 2000 and in 2005 became consent based.[7] All states agreed to transfer their drivers licence registers to the national body, however, New South Wales continued to maintain their register. There have also been delays in implementing this arrangement. More than 1 039 261 Australians have now been registered on the AODR.[8]

On a positive note for Tasmania, as at 31 January 2008, 180 494 Tasmanians had registered their intent to donate their organs. However, only 28 215 of these people have legally registered their consent to donate under the new system.

For the last seven years Australia has experienced consistent organ waiting lists of approximately 1800 individuals.[9] The average waiting period for kidneys has risen to 3.8 years and there are hundreds of others waiting for pancreases, lungs and hearts. Although the AODR has improved the process of registration, confusion as to the validity of the consent remains.

Each year in Australia approximately 700 people receive transplants from deceased donors. One donor is able to provide organs for up to 10 recipients.[10] Australia compares favourably to other countries regarding both the successful transplantation of organs and the number of organs retrieved per donor.

The adequacy of the current system was evaluated against an "opt-out" system. Issues including what constitutes "informed consent" and the level of understanding required in order to make a decision regarding organ donation were considered, as well as the methods used to record the number and success of donations.

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[7] Medicare Australia – AODR information
http://www.medicareaustralia.gov.au/provider/patients/aodr/index.shtml (accessed 7.2.2008).

[8] Medicare Australia – AODR information
http://www.medicareaustralia.gov.au/provider/patients/aodr/stats.shtml#consent (accessed 12.3.08).

[9] National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 11.

[10] Kidney Health Australia http://www.kidney.org.au/

Individuals wishing to register their consent on the AODR are required to obtain a form from Medicare Australia or download the form from their website. These forms are also issued with renewals of Medicare cards. A large-scale mail out to homes was undertaken when the changeover to the consent system occurred, with little impact on consent rates.

When the system of organ donation registration changed over to a "consent based" model in 2005, the Federal Health Minister decided that the physical signing of a form was imperative for legal consent. Other mediums of consent, such as via text message and the internet, were precluded. Key stakeholders, such as Associate Professor Neil Boyce, the Executive Officer of LifeGift Victoria, are of the view that the current system is sufficient and that it does validly enable interested individuals to consent.[11]

Adequacy

Dr Matthew Jose, Staff Specialist Nephrology, Royal Hobart Hospital, commented that many relatives asked him how to register under the current system. He suggested that –

> "Even amongst people who have direct family relatives there are those who are still ignorant of the system, so I think the education of the public is not adequate... Even though we have a high rate of people registered on the organ donor registry, the next steps are also stepped down significantly so that the number of donors and the number of ICUs that check the donor registry is very poor."[12]

Mr John Yeats, who has personal experience as a donor parent, as well as awaiting a transplant himself, said he believed that the systems are :

> "… probably quite adequate if people knew about them. I say that because I have addressed a number of people or spoken to a number of people, most of whom think it is still a matter of putting a tick on your driver's licence application. They are all wrong. Other people I have spoken to, and quite recently, have suggested that they have done all sorts of things to try to find out what they do now, but nobody was able to say, 'Just go to the Medicare offices'. Two people actually went to Service Tasmania to say, 'I have signed my driver's licence but I believe that's no longer a valid way to do it, so what do I do?' They don't know. People are simply just not aware…"[13]

In a written submission provided by Timothy Matthew, the Medical Director of Kidney Health Australia (KHA), several flaws of the system were expressed –

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[11] Boyce, Associate Professor Neil, Executive Officer, LifeGift Victoria, Australian Red Cross Blood Service, Written Submission, p. 1.

[12] Jose, Dr Matthew, Staff Specialist Nephrology, Royal Hobart Hospital, Transcript of Evidence, 1 October 2007, p. 38.

[13] Yeats, Mr John, Transcript of Evidence, 5 October 2007, p. 44.

> "The AODR is not routinely accessed by health professionals at the time when organ donation is being considered. Reasons for this include a belief by some Intensive Care physicians that to do so may be considered a breach of faith with the families, apathy and concerns regarding the accuracy of the Registry database.
>
> The number of people on the "consent" register is low (even after its existence for 3 years) due to poor publicity about how to register, confusion in people's minds that previous registration on the Motor Vehicle Registry would be carried over to the new Registry and the complexities of the registration process.
>
> No registration of intent or consent to donate has been demonstrated anywhere in the world to have increased the donation rate"[14]

Whilst the drivers licence system is effective, as people are aware of the opportunity to opt into organ donation by ticking the box at the time of licence renewal, there are several drawbacks to registration through such a system. The AODR register sees a vast majority of positive registration with only 0.2% of those recorded being a definite desire not to donate. In contrast the percentage of 'no' registrations in NSW is around 30%.[15] One factor that is thought to impact on this discrepancy is that people are forced to answer yes or no at the time of renewal. As not all those renewing their registration have always considered the organ donation issue fully, they are more likely to reject the proposition.[16] Having a registered desire not to donate prohibits the donation of organs. In fact, with further consideration or discussion these people may have been pro donation, but their family will not get the opportunity to choose.

Informed consent

Before organ donation can occur, either the donor must have consented in an informed way prior to death and/or the next of kin must consent after death. Currently in Australia, registration of consent is via the Australian Organ Donor Register and the relevant forms can be downloaded from the internet, but they have to be physically signed to be valid.

One question raised was whether the registration rate could be increased by an online system being established.

Ms Laraine Donnelly, questioned whether web sites could constitute informed consent. After looking at one of the sites for enrolment for Australia, she said that –

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[14] Matthew, Timothy, Medical Director, Kidney Health Australia, Written Submission, pp.1-2.

[15] National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 127.

[16] Ibid.

> "…you couldn't consider it to be informed. There was a little bit of detail about some of the procedure … but it certainly was not wide enough to be considered informed consent."[17]

Others felt that it could be sufficient and a good reform, with comments such as –

> "I consent to such funds being transferred hither and thither on the Internet, I can consent to all sorts of things."[18]

Further, Ms Laraine Donnelly was of the opinion that personal communication should be involved.[19] Generally, there was discussion about whether the form itself, in its current state, provided appropriate opportunity for information to be conveyed to the public.

When questioned on this matter and in relation to the adequacy of the form generally, Dr David Boadle, the Chief Medical Officer, Tasmanian Department of Health and Human Services, replied –

> "…On one hand I would like to say yes but I am always wary of a process that does not involve a discussion between an informed person (and someone) who is trying to consent… I still maintain, from years of clinical practice, that that is far and away the best way to do things, sitting down with someone who understands and can answer your questions and you have an exchange of information. No matter what quality of information you provide in written information to go with a consent form I still think it is the exchange between human beings that should give the better understanding and truly informed consent of what it will mean to me. What happens to my body is an important question."[20]

When questioned about the suitability of the same form and whether it was the appropriate one to be signing, Dr Jose said –

> "I do. I think it should be consent but, again, when I changed my address and signed up the other day, to sign a consent form from a medical perspective requires informed consent. It was too easy for me to re-register and re-consent without any proper informed consent process. So I do not believe when I re-did my address and things that it prepares you properly for what you are signing up for. I am not sure whether it stops people at that point because they do not understand really what they are getting into."[21]

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[17] Donnelly, Ms Laraine, Transcript of Evidence, 2 October 2007, p. 8.

[18] Boadle, Dr David, Chief Medical Officer, Department of Health and Human Services, Transcript of Evidence, 1 October 2007, p. 77.

[19] Donnelly, op. cit., p. 8.

[20] Boadle, op. cit., p. 78.

[21] Jose, op. cit., p. 38.

It was suggested that the senior next of kin should also sign the registration form to attest that they had discussed the issue. In this regard, when asked if such a change would improve organ donation rates, Dr Boadle replied –

> "It could be. It would be interesting to ask some families and see what they would think if the senior next of kin had to contribute to this process. There could be a counter-intuitive response where someone might say, 'If I'm signing this, that means it has to happen'. The senior next of kin might feel they are being locked in to some extent so it would be interesting to test that theory. You would think it would improve things."[22]

One suggestion, from Ms Margaret Clarke, a Christian Science representative*,* was that decisions should be reviewed at regular intervals and she recommended this occur every five or ten years on the basis that views change over a period of time.[23]

The National Clinical Taskforce on Organ and Tissue Donation's report of January 2008 highlighted the fact that a distinction between expressions of 'intent' and 'consent' had little real bearing on the process of organ donation and this was backed up by the information provided to the Committee by medical professionals.[24] The report noted that the register made it easier for next of kin to make informed decisions of their loved one's wishes, but that in practice under the present legislation, family members would always be consulted to confirm the decision. Fundamentally, a registration of consent is only the expression of a desire to donate, and the immediate family makes the ultimate decision.

Such a view negates the need for programs to further encourage consent signings by those who have already lodged intent undertakings as they are of no practical difference.

Additionally, such an observation indicates that the internet would provide an appropriate forum by which to register consent to donate. The National Taskforce report supported such a finding stating that online registration would satisfy the necessary expression of consent as required by the Tasmanian legislation.[25]

Opt Out Process

The Committee also investigated whether an opt-out system of organ donation would be beneficial in increasing the Tasmanian organ donation rate. Such a system operates with quite a high level of success in countries such as Spain, Singapore and Austria.

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[22] Boadle, op. cit., p. 85.

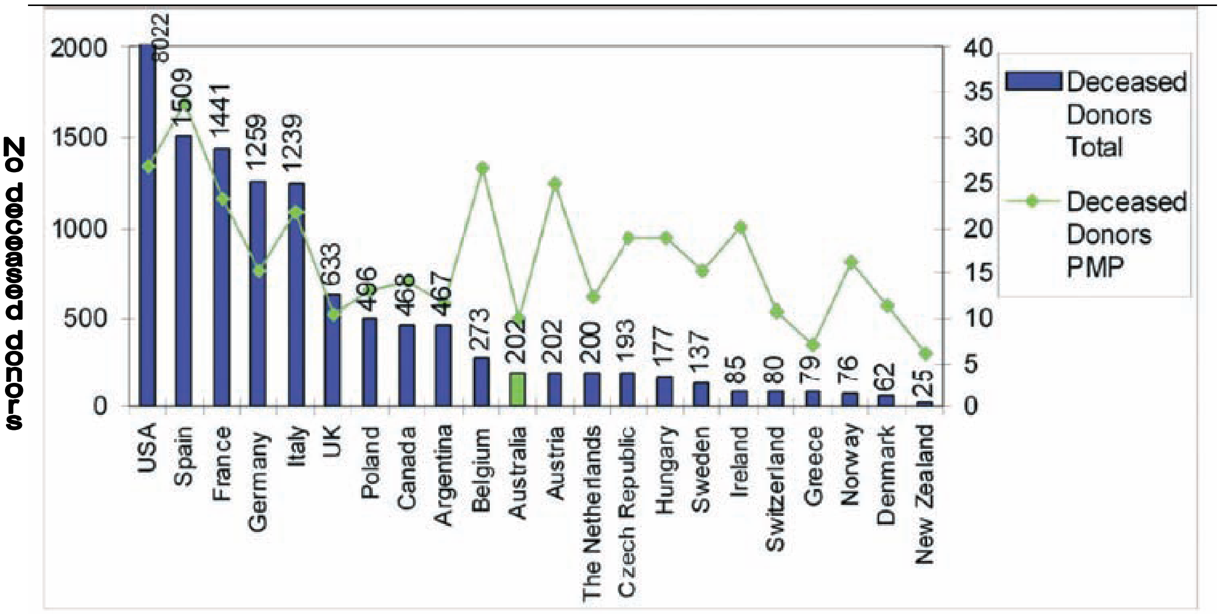
[23] Clarke, Ms Margaret, Christian Science Representative, Transcript of Evidence, 1 October 2007, p. 67.

[24] See the section on consent in chapter 4.

[25] National Clinical Taskforce on Organ and Tissue Donation, op, cit., p. 125.

In relation to other countries, Australia has a relatively low rate of organ donation at around 10 donors per million population (dpmp).

Figure1: International donor statistics 2006 (annual total number and dpmp)[26]



Tasmania's donation rate has fluctuated significantly over the last five years, ranging from 4 to 16 dpmp and sometimes lagging well behind other states. South Australia has recorded the best performance.

It was submitted to the Committee that the donors per million of population (dpmp) rating was not an ideal way to measure the success of organ donation within Tasmania.[27] Due to the small population size, a large fluctuation would occur in the rate when only a very small change in donors was experienced.[28] Over the 2001-2006 period the number of donors from Tasmania were 6, 2, 2, 2, 8 respectively.[29]

Dr Boadle made the point that –

> "…When looking at the indicator for the success of the organ donation system, we have consistently made the contention that we should be measuring the conversion rate rather than the donor rate per million of population. We feel that the donor rate per million population is a relatively crude indicator and doesn't take into account variances in the members of the community who become eligible to be donors. In other words, if there are more cerebral haemorrhages and car accidents in a particular country or jurisdiction than another, the number of people eligible to be organ

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[26] National Clinical Taskforce on Organ and Tissue Donation, op.cit., p. 12.

[27] Boadle, op. cit., p. 73.

[28] Ibid., p. 73.

[29] Australian and New Zealand Organ Donation Registry (ANZOD) 2007 Report, Leonie Excell, Kathy Hee and Professor Graeme Russ eds. p. 2.

> donors is going to vary. To some extent your community would desire there to be few people eligible to become organ donors because there would be fewer people becoming brain dead, for whatever reason."[30]

This approach was supported by the National Clinical Taskforce on Organ Donation which indicated that "an appropriate denominator should enable an assessment of what has been achieved against what was possible."[31] Further, Professor Anthony Bell, Deputy Director Medical Services, Medical Co-Director Clinical Services, Royal Hobart Hospital, stated that Tasmania has a unique problem in that it cannot accept donations from non-beating heart donors due to the services available and an inherent issue of scale.[32]

The legislation that guides donation in Tasmania is the *Human Tissue Act* 1985 and although this Act is very similar to those that operate in other states, it is the processes involved that differ. The onus to show consent and the requirements of expression are altered between the states.

The Committee heard evidence that South Australia had the best model for overseeing organ donation. It is based on the Spanish model of organ donor facilitation and involves dedicated teams in intensive care units, exclusively responsible for organ donation.[33]

According to Dr Megan Alessandrini from the University of Tasmania, who studied organ donation motivations –

> "The evidence is that it [the Spanish model] is dependent enormously on coordination and on relatively small teams of people working together with a clear goal in mind."[34]

This model has increased the number of organ donations in Spain.

With regard to a change in system, Ms Sue Robertson, Clinical Nurse Manager in the Renal Unit at the North West Regional Hospital, was of the view that –

> "…people who are passionate about it, that do not want to donate their organs, will be the ones that make sure they opt out and you will not have – that terrible phrase – 'wasted opportunities.'"[35]

Whilst Ms Donnelly was concerned that –

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[30] Boadle, op. cit., p. 73.

[31] National Clinical Taskforce on Organ and Tissue Donation, op. cit. p. 13.

[32] Bell, Professor Anthony, Deputy Director Medical Services, Medical Co-Director Clinical Services, Royal Hobart Hospital, Transcript of Evidence, p. 20.

[33] Jose, op. cit., p. 45.

[34] Alessandrini, Dr Megan, University of Tasmania, Transcript of Evidence, 14 February 2008, p. 2.

[35] Robertson, Ms Sue, Clinical Nurse Manager, Renal Unit, North West Regional Hospital, Transcript of Evidence, 5 October 2007, p 11.

> “One of the problems with an opt-out system is the right to choose for many people who may have their mental or emotional health impaired.”[36]

Several witnesses supported an opt-out system,[37] however, many professionals in the medical field were more reluctant. Some indicated that they had previously advocated such a move, but now do not consider it beneficial. Professor Boyce, Executive Officer, LifeGift Victoria, Australian Red Cross Blood Service, believes that there are two reasons why the current system is preferable to an opt-out process –

> “Firstly, I do not think culturally that Australian health care professionals will ever accept an opt-out system. Even in countries such as Spain that have legislated opt-out they still function as opt-in with consent for every donor. Secondly, there are significant ethical issues about the necessary level of information that has to be consistently given to the community to get genuine informed opting out.”[38]

Professor Robert Jones, Director Liver Transplant Unit, Austin Hospital, was also against any change occurring –

> “Experience around the world is that the opt-out hasn’t seemed to make a lot of difference. So I think, just in pragmatic terms, it causes a lot of angst and probably the end result would be not a vast difference in donor rates. So I think just in practical terms it perhaps may not be worth the effort in trying to persuade the public or the parliament that that is the thing we should do. Initially I thought it was an excellent idea but I have come around to feeling that it probably isn’t the key to increasing donation rates.”[39]

The National Clinical Taskforce on Organ and Tissue Donation rejected the introduction of opt-out legislation in its final report released this year,[40] stating that –

> “The Taskforce recommends against the introduction of a presumed consent (opt-out) approach by any Australian state or territory. It is not expected that legislative change in isolation can bring about a substantial increase in donation rates, as there are other relevant factors that influence donation rates. For example, a number of countries with a presumed consent system also adopt a presumptive approach to the decision

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[36] Donnelly, op. cit., p. 7.

[37] Gray, Andrew, Transcript of Evidence, 2 October 2007, p. 39 and Mr Aaron Mackrill, Transcript of Evidence, p.7

[38] Boyce, Professor Neil, Executive Officer, LifeGift Victoria, Australian Red Cross Blood Service, Transcript of Evidence, 1 October 2007, p. 16.

[39] Jones, op. cit., p. 1

[40] Macdonald, Emma, “Automatic donation rejected - Organ taskforce spurns proposal” *The Canberra Times, Sunday 17 February 2008,* http://canberra.yourguide.com.au/news/local/general/automatic-donation-rejected-organ-taskforce-spurns-proposal/1184374.html accessed 28.2.08.

> about donation made by the family. Other factors, such as health care resourcing decisions and variations in mortality rates (such as road accident fatalities and stroke), also have an effect on donation rates. In the Australian context, such a move would most likely be destabilising. Surveys have indicated that there is a pre-existing element of medical mistrust within the Australian community, which in relation to organ, eye and tissue donation needs to be countered through education and awareness campaigns (Eureka Strategic Research 2007). The Taskforce considers that a presumed consent system may feed these fears and most likely lead to an increase in the proportion of registrations of objections to donation. It might also lead to clinicians being less likely to proceed with initiating the donation process. When Australia's predominant social attitudes and legal traditions are considered, the principle of informed consent model better balances individual rights with the community's need for organ, eye and tissue donation."[41]

Universal Registration

Another proposal to increase the rate of registration for organ donation was "universal registration." Such a campaign was outlined in a submission to the Western Australian Health Department in 2006 suggesting an intense campaign be conducted until 2010 at which point if an 80% AODR sign- up rate had not been recorded, a universal registration system would be implemented.[42] The study claimed that such a scheme -

> "would maintain freedom of choice, since each Australian would be called to give his or her own opinion, whether consent or refusal."[43]

Professor Boyce does not believe that a system of universal registration would be warmly welcomed in Australia, because we –

> "…are anti-authoritarian and are likely, in the equivalent of the Australian salute, to say no, in the context of that being, 'No, I don't want you to tell me what to do.' They tried it in Texas. They said everyone had to make a decision and they got an 80 per cent 'no' response."[44]

Evidence indicated that whilst small changes to the system may be desired, a radical overhaul of the underlying philosophy is not warranted. Instead, the focus should be on the reports already published in the area in relation to key components to donor rates.

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[41] National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 157.

[42] Department of Health, Western Australia, "Project Forward", 2 November 2006, p. 6.

[43] Ibid.

[44] Boyce, Transcript of Evidence, op. cit., p. 32.

The May 2005 report into the potential for organ donation in Victoria by Helen Opdam and Bill Silvester, suggested that in order for the optimal level of donation to occur, organisations need to work on –

- “Ensuring that the Clinical Governance framework in Victorian hospitals includes an explicit accountability for the organ and tissue donation performance achieved within our Health Services.
- Ensuring that Intensive Care Units take a leadership role within their hospitals in managing potential donors, including confirming any known wishes of any potential organ and tissue donor regarding donation and discussion of organ donation with families. Development of this leadership role would be assisted by the appointment of an Intensivist (part-time) with the responsibility for directing a program of activities to optimise the identification and management of potential donors within their hospital.
- Ensuring that all staff discussing organ donation with families has appropriate experience and the requisite skills. One model for training is the Medical ADAPT workshop.
- Ensuring the provision of regular feedback to individual hospitals on key organ and tissue donation performance indicators adjusted for the number of potential organ and tissue donors (such as rates of request, consent and organ and tissue donation.)”[45]

These suggestions reinforce earlier recommendations by the same authors in a 2004 journal article, where it was recognised that three areas needed to be addressed in order to increase the donor rate –

> “1. Raise the consent rate. The consent rate of 59% in this study is comparable to that of other reports, which range from 45 to 84%.
> Various factors influence the consent rate, including the level of public support and the assiduousness with which organ donation is requested. Using overly persuasive techniques may result in some families consenting who otherwise may not. Coercion or repeated requests are not acceptable in Australia.
> Consent is more likely if the request is made by individuals who are informed about and support organ donation, particularly organ donation agency staff. In Australia ICU specialists make nearly all requests for organ donation and see this as their responsibility. Coronial non-consent of 1.5% in this study was low compared with other reports.

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[45] Helen Opdam and William Silvester, Joint Report of the Department of Human Services and LifeGift, the Victorian Organ Donation Service, “Potential for Organ Donation in Victoria: An audit of hospital deaths”, January 2002 to October 2004, May 2005, p. 3.

2. Failed physiological support [that is, appropriate maintenance of the brain-dead beating-heart organ donor]. The rate of failed physiological support, at 5% of consented potential donors, is low compared with other studies (4-21%). A further reduction may be possible with optimal management of potential donors.
3. Lack of identification and support to brain death of potential donors."[46]

Professor Jones also highlighted that whilst registration is an important component, the most important step is ensuring that the processes within hospitals are well organised.[47]

Conclusions

The Committee concludes that :

1. Imposing an 'opt out' system of registration of consent may significantly reduce the number of people willing to register consent to organ donation.

2. Tasmanians who have previously indicated their intent to donate on their drivers' licence, are generally not aware of the need to formally and legally register consent through the Australian Organ Donor Register.

3. Informed consent is a complex matter. It is difficult to ensure that a person has understood all potential risks and benefits of a procedure, including organ donation.

4. Online registration would satisfy the necessary expression of consent as required by the Tasmanian legislation.

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[46] Helen Opdam and William Silvester, 'Identifying the potential organ donor: an audit of hospital deaths" *Intensive Care Medicine (2004)* 30: 1390-97, pp. 1396-6.

[47] Jones, op. cit., pp. 2, 10.

The Adequacy and Impediments of Tasmania's Approach

Chapter 3

TERM OF REFERENCE (2)
The adequacy of Tasmania's approach in identifying potential donors and facilitating the donation and procurement process; and

TERM OF REFERENCE (3)
The impediments, if any, causing Tasmanians to have the lowest organ donor rates in the nation and the net worth to Tasmania of having an organ donor rate equal to the best in the nation.

Professor Boyce commented on the adequacy of Tasmania's approach to identifying potential donors –

> "…the simple answer is that we don't know because no-one has looked, at least to my knowledge. I would be a strong advocate for putting in place routine systems to measure the performance of donation systems. As I say, I think that missing even one potential donor is a significant matter."[48]

Audit

The Committee received evidence in relation to the need for an audit of current practices in Tasmania, in order to assess donation performance. Similar studies have been conducted in most other states.[49]

Evidence submitted by Ms Carolyn Mackintosh, the Health Services Manager from Kidney Health Australia (Tas), indicated that –

> "A Victorian study looked at how they could increase their donor rates between 2002-04 and they said that identification within the hospital system of potential donors was a key – educating the hospital staff and raising their awareness about organ donation in the processes within their hospital system. It is very important for them to understand how they could better effect an increasing donor rate, and even obtaining consent from relatives, with better training and education for the clinician who have to approach families. If they are more confident and have some experience behind them, they can effect an increase in getting a family's consent."[50]

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[48] Boyce, Transcript of Evidence, op. cit., p. 16.

[49] Opdam, Helen and Silvester, William, 2006 report, op. cit, and Jose, op. cit., p. 36.

[50] Mackintosh, Ms Carolyn, Health Services Manager (Tas), Kidney Health Australia, Transcript of Evidence, 1 October 2007, p. 51.

Dr William Silvester from the Joint Faculty of Intensive Care Medicine, outlined the audit process in Victoria :

> “The Auditor is usually an ICU nurse who is employed one day a week or one day a fortnight to do the auditing, depending on the size of the hospital, and that auditing means that they get a copy of all the deaths from the previous week from the Medical Records Department. They can quickly eliminate the ones that have come in that would not be appropriate. For example, those who had come in with cancer and died from cancer or those who are over the age of , say 75, or under the age of two, or those who have died from severe infection. That usually ends up leaving … two or three patients. They then call the medical records, they look through it – did this person die in ED or in ICU? Was the cause of death due to a severe head injury that was irreversible and could have possibly lead on to brain death? So they identify these issues through looking through notes, they fill in a template and then at the end of this auditing process there is a question as to whether this may have been a potential donor. It is then referred back to the central group [and determined if] …this is a potential person; we need to refer this through to our panel of intensive care specialists. We then consider this and then our panel look at them all and say yes, that one was missed, that one wasn’t, that one was, then we collect that data prospectively”.[51]

Dr Silvester explained further how hospitals are advised regarding missed donors :

> “In terms of doing a proper audit … you need to close the loop by providing appropriate feedback, but we do it in a sensitive, professional way so that they do not feel as though we are telling them off and we use it as an opportunity to gain information and help them to take ownership and identify where their problems are and fix them”.[52]

Professor Boyce outlined the purpose and use of an audit –

> “It looks at who could be potential donors and then determines what happened to them and why, by both looking at medical records and talking to the clinicians involved. It brings out issues such as, ‘We didn’t want to approach the family because we thought they were too upset’, or ‘We didn’t have access to nuclear medicine at the weekend so we couldn’t determine brain death’, or “We thought they were Jewish so we didn’t think it was appropriate’, or ‘We got the junior staff to do the approach and the family said, ‘You’ve got to be joking’, or they asked a question that the junior staff couldn’t answer and so they said no’. It

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[51] Silvester, Dr William, Joint Faculty of Intensive Care Medicine, Victoria, Transcript of Meeting, 26 November 2007, pp. 30-31.

[52] Ibid., p. 31.

> follows right through to the outcome and provides very valuable information about what is going wrong. Some of it may not be fixable but much of it is. Much of it is just health system belief, attitude and behaviour that can be changed."[53]

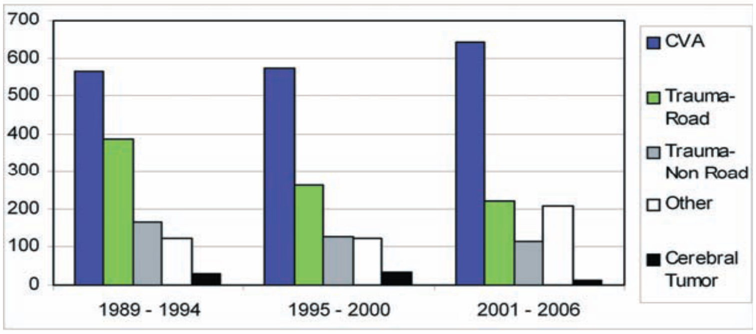
Causes of death

The Victorian audit of organ donation suggested that the lower number of potential donors in that state may relate to the lower number of road and firearm traumas.[54] This view was supported by Professor Bell who highlighted the fact that dying of brain death was a rare thing in 2008. He said that –

> "We have the same number of head injuries or traumas coming in but basically most of them survive these days. Brain death is a very rare occurrence."[55]

Figures sourced from the Australian and New Zealand Organ Donation Registry (ANZOD) suggest that the incidence of road trauma causing death which lead to transplantation is decreasing, whereas cerebrovascular accidents are increasing.[56] In 2006 road traumas accounted for only 16% of donor deaths.[57]

Cause of organ donor death, 1989–2006



(Source: ANZOD 2007)[58]

The National Taskforce Report found that –

> "[C]auses of death among deceased donors have changed over time in Australia, with road deaths decreasing. As a result, the donor profile is changing from young brain trauma patients of generally prior good health to older donors with cardiovascular and other co-morbidities."[59]

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[53] Boyce, Transcript of Evidence, op. cit., p. 17.
[54] Opdam et al., op. cit., p. 253.
[55] Bell, op.cit., p. 17.
[56] National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 64.
[57] ANZOD 2007 Report, op. cit., p. 8.
[58] National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 63.
[59] Ibid., p. 59.

Whilst this is an important point to take into consideration, Dr Jose raised an issue of concern relating to the rate of donation in Tasmania, stating –

> "I do not think it is adequate. If you take, for example 2005-06 and look at the variation in the number of organ donors in the State between these two years, I think there were two organ donors in 2005 and eight in 2006. I know that we have small numbers but I cannot believe there is a 400 per cent difference in people coming through the hospitals over that year. So I do not think it is adequate but we do need the audit to look at it."[60]

Professor Boyce outlined that –

> "…consistently Tassie has the lowest donor age in Australia. I think it is very unlikely that that is just a statistical fluke over the last 18 years; you have always had the youngest donor age. To me, it suggests that there might be a systematic bias toward thinking of it in younger people but not in older."[61]

The mean age for Tasmanian donors in 2006 was 36.4 years, whilst most other states had a figure in the 40s.[62] Organ donation can occur in those aged up until their mid 70s and the oldest cataract donor (tissue donor) to date was 103.[63] If older donors are not being considered, this could mean that many potential organ donors and their families are not given the option to donate.

Possible Impediments

Dr Jose suggested that the outcomes of those organs sourced from Tasmania need to be taken into consideration when assessing changes to the current system. The time delays in processing and the age of the donor need to be measured against their respective outcomes, to determine if there is value in converting more potential donors into actual ones.[64]

Professor Bell, when discussing the distances that it might be necessary to move a patient in order to donate, said that –

> "[W]hen you become brain dead you usually have about 24 hours of stability with quite straightforward treatment. It is a very reasonable thing, if you have talked to the family, to have the patient transported to Hobart, prove they are brain dead and then do an organ donation, especially if you know that is what the patient's wishes were."[65]

Whereas Professor Boyce observed that –

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[60] Jose, op. cit., p. 41.

[61] Boyce, Transcript of Evidence, op. cit., p. 27.

[62] ANZOD 2007 Report, op. cit., p.5.

[63] David Hookes Foundation "Organ and Tissue Donation" brochure.

[64] Jose, op. cit. pp. 36, 42.

[65] Bell, op.cit., p. 19.

> "The need for air transport of both my staff and the retrieval surgical teams result in longer times from determination of suitability for donation to actual donor surgery. These times have been a median of 19-24 hours in recent years in Tasmania. Whilst this measure of the 'timeliness' of organ procurement processes is similar to the times recorded in the Northern Territory and Western Australia in recent years, it is longer than the 13-18 hours median times recorded in the remainder of the mainland states."[66]

Dr Reid, a specialist in Respiratory Medicine at the Royal Hobart Hospital, added that –

> "The limiting thing in Australia is distance and distance for lungs especially is really important because they are fragile organs and they deteriorate very quickly when they have been removed from their natural environment. It is called ischaemic time which is low oxygen and low nutrition and damage happens very quickly."[67]

Ultimately, all knowledge of donor rates in Tasmania and the outcomes of those who donate is based largely on "hearsay and innuendo" and according to Dr Jose there is a great need for supporting data.[68]

Professor Bell's evidence suggests, however, that there will still be a percentage of patients who would have been eligible to donate, but because their death was caused by cardiac arrest, Tasmania is not able to conduct the necessary processes.[69] Further, he believes that "we just do not have the ability to do the audit when as a State, we appear to have, at the best, three to five organ donors a year."[70] These factors also affect the rate of organ donation in Tasmania.

Professional Knowledge and Compliance

A further impediment considered was the assignment of responsibility for the organ donation process.

Professor Boyce commented that –

> "Whilst I think many doctors and nurses take donations seriously, there are still a substantial number who would say, 'It's not my responsibility. This isn't my job. I'm really busy doing other stuff'. They do not articulate whose job it is and, clearly, if it isn't the job of those caring for potential donors, I cannot for the life of me think whose job it is. Some emergency and ICU doctors in particular will argue that it isn't their job, that they are just too busy."[71]

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[66] Boyce, Written Submission, op. cit., p. 2.

[67] Reid, Dr David, Specialist, Respiratory Medicine, Royal Hobart Hospital, Transcript of Evidence, 1 October 2007, p. 5.

[68] Jose, op. cit., p. 41.

[69] Bell, op. cit., p. 20.

[70] Ibid., p. 26.

[71] Boyce, Transcript of Evidence, op. cit., pp. 17-18.

The lack of clearly assigned responsibility in the current Tasmanian system is likely to impede donor rates. The schemes which experience the highest donation rates are those which are the most coherent in their planning and comprehensiveness.

Due to Tasmania's small population, there is an extremely low number of people who will become potential organ donors in any one year. Only two to three percent of deaths (at most) occur in a situation that allows donation[72] and this means that the figure in Tasmania is generally a low single digit when it comes to actual donor numbers.

Professor Boyce, whilst addressing the issue of funding, said –

> "We have to get a grip; this is a rare event. In Tasmania, if we were to double your donor rate, we would use perhaps six or eight ICU beds for one day in a year."[73]

The submission from Ms Mackintosh and Mr Farrell on behalf of KHA, outlined the following perceived impediments to organ donation in the state –

> a) "Lack of dedicated staff in Tasmania to facilitate organ donation (such as occurs in all other States through the Organ Donation agencies)
> b) Confusion in the public mind about the 'consent' registration
> c) Lack of participation in the National Collaborative on Organ Donation that has shown sustained improvement in the United States hospitals and in the first 12 months of the Australian program has lifted donation rates in poorly performing hospitals by a substantial amount."[74]

<u>Lack of Local Coordinator and Agency</u>

In his written submission to the Committee, Mr Timothy Matthew, of KHA, suggested that –

> "The absence of a dedicated state based organ donation agency (as exists in all mainland States) is believed to account at least in part for the poor performance of Tasmania…KHA is strongly supportive of the appointment of a full-time organ donation coordinator, with State-wide responsibilities, to improve the awareness of organ donation in Tasmanian hospitals, to assist in training hospital staff in the identification and best care of potential donors and to participate in the facilitation and management of actual donors. It has been reported to KHA anecdotally that medically suitable donors are being missed in the

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[72] National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 49.
[73] Boyce, Transcript of Evidence, op. cit., p. 18.
[74] Kidney Health Australia, Written Submission, 7 August 2007, p. 2.

> current Tasmanian system. The wildly fluctuating actual donor rate is further testimony to this occurrence."[75]

Professor Boyce also supported the creation of an organ donor coordinator role suggesting –

> "…a coordinator who is closer to what I call a liaison nurse and that is their primary credibility is they are an ICU or ED nurse who takes on organ donation as a special cause. It might even be two such nurses in Hobart and Launceston, for example, who work half a day a week in this particular role. You have to get the data, you have to feed it back to people but you also need to be upskilling them in identification and management of donors…there is a skill in managing the unstable brain dead or approaching-death donor and it is something that is a pretty rare event and people do not necessarily have much experience in it as individuals, if that makes sense. Even at a hospital like the Alfred that is our biggest donor centre, we have looked and most health care professionals themselves see only one donor every year or two, so if it is even a less common event it becomes really important to have protocols, procedures and access to support."[76]

Professor Bell agreed and explained that –

> "People have pushed for many years to say that we need an organ donor coordinator. The complexity of it has become such that it is now a role that we do need. If you had asked me five years ago, I would have said it was hard to see the need. But it is a different business now – it is just so complex; you have to keep up with it, you have to educate people….We need the organ donor coordinator. I would not have a person – I think it is a role for three or four people, even if it is in a part-time role with their other positions to basically keep on top of all those things."[77]

According to evidence presented by Mr Bernard Farrell, the Chairman of Kidney Health Australia National Consumer Participation, the cost involved in funding such a service would probably be covered by the savings in only two successful kidney donations.[78]

The National Taskforce report outlined the key roles of an Organ Donor Coordinator –

> "Organ Donor Coordinators are central to the process of organ, eye and tissue donation, as they –

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[75] Matthew, op. cit., p.2

[76] Boyce, Transcript of Evidence, op. cit., p. 18-19.

[77] Bell, op,cit., p. 26.

[78] Farrell, Mr Bernard, Chairman of Kidney Health Australia National Consumer Participation, Transcript of Evidence, 1 October 2007, p. 53.

> - provide a 24 hour on call service and coordinate all the tasks involved in the donation process;
> - provide support to clinical staff and to the family of the potential donor;
> - are responsible for ensuring that the legal, ethical, clinical and procedural requirements of the consent, referral and retrieval processes are met;
> - have close contact and cooperation with the donor family, donor hospital and the surgical retrieval teams;
> - provide ongoing bereavement support and counselling to donor families over time;
> - are responsible for the documentation of the many relevant protocols and procedures undertaken; and
> - play a pivotal role in the education of health care professionals (eg. medical, nursing and allied health) regarding all aspects of brain death and the donation process."[79]

The Committee met with relevant stakeholders in Melbourne and Adelaide regarding models for organ donation existing outside the LifeGift model of Victoria/Tasmania and New South Wales. Evidence suggested that the Victorian model may lack some potential for results offered by the more hospital-based South Australian scheme. A suggestion received from South Australia was for Tasmania to investigate forming its own organ donor agency and working in collaboration with one of its mainland counterparts. Such a system is currently employed by the Northern Territory which has its own coordinators and agency, but collaborates strongly with the South Australian Organ Donor Agency.

One reason to maintain the current link with the Red Cross, according to Dr Alessandrini's research, is that –

> "It seems that there is considerable mistrust first of all of business and also of government institutions, whereas with non-government organisations there is quite a high level of trust….They will not necessarily think that they are particularly efficient but they are more likely to trust them to do the right thing."[80]

National Organ Donor Collaborative (NODC)

A further contentious issue was Tasmania's non-involvement in the National Organ Donor Collaborative. Ms Mackintosh from KHA described the history of the Collaborative as being based on a successful scheme in America where hospitals pooled their resources in order to create guidelines for best practice in organ donation and increase organ donor rates.

> "In the space of three years they got their organ donor rate up by 20 per cent. Australians Donate has been funded to start up

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[79] National Clinical Taskforce on Organ and Tissue Donation, op. cit., p 47.

[80] Alessandrini, Dr Megan, Transcript of Evidence, 14 February 2008, p. 10.

> something similar in Australia. It has been going for just over a year now and several hospitals around Australia were invited to join this trial. They were given the background information from America and the hospitals then shared in these learning sessions. They met regularly; they provided feedback on what worked, how they were improving their rate, what they were doing that worked, what did not work, so then they could go back to the hospital and pinch somebody else's ideas that sounded really good. A bit of trial and error. They found about a 30 per cent increase in donor rates in those hospitals that are participating in Australia."[81]

No Tasmanian or Queensland hospital was included in the 22 initially involved in the NODC.[82] When asked about the lack of direct Tasmanian involvement in the NODC, Dr Boadle replied –

> "We canvassed the opinions of our intensive care specialists around the traps and they felt they could not re-prioritise another part of their duties to be a part of the National Collaborative. Quite frankly we quite simply have to take on a number of issues in Tasmania…We made a pragmatic decision, I think – and an appropriate one – to say we won't participate in the National Collaborative but we will keep an eagle eye on it. We will get most, if not all, of the benefits of that process because we are privy to all the outcomes and so on."[83]

It seems that the NODC is proving effective with the figure for organ donation over the 06-07 year at 225. This number is the highest recorded since 1989 and is a 25% increase on the previous year.[84]

The Board of Australians Donate believe that expansion of the Collaborative is crucial due to its very promising early results. Some evidence from the US experience suggests that over time a 75% conversion rate can be attained.[85] Of the 22 hospitals involved in the initial stages of the Collaborative, 20 are moving into a consolidation stage and a further six have joined the initiative.[86]

At their meeting on 7 December 2007, Australian Health Ministers approved the creation of a clinical and government committee to oversee organ donation and relevant procedures. This body will administer the NODC, which has had funding approved until at least 30 June 2009, into the future.[87] Australians Donate ceased to operate at the end of March 2008.

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[81] Mackintosh, op. cit., p. 52 (This increase in donation rate was 32.4%) per figures from Australians Donate November 07.

[82] Australians Donate, Written Submission to the Committee, August 2007, p. 8.

[83] Boadle, op. cit., p. 87.

[84] Australians Donate, op. cit., p. 9.

[85] Ibid., p. 9.

[86] Australians Donate November 07 Newsletter.

[87] Roxon, The Hon. Nicola MP, Minister for Health and Ageing, "New national efforts to lift organ donation rates", Media Release, 17 February 2008, p. 2.

Terminology and Brain Death

Associate Professor Newell, a medical ethicist at the University of Tasmania, suggested that the, "…terminology used to speak about the "harvesting" of organs, [was] hardly an appropriate or helpful terminology."[88]

He commented that –

> "There is no doubt that contemporary practice has learnt from these historical problems and that we see a markedly different situation. However, some of these images and concerns are enduring. In addition, there is still the concern amongst some as to the adequacy of brain death criteria utilised".[89]

Further evidence suggested that the definition of brain death was seen as problematic by several groups. Brain death as a concept was first developed in 1968 and has caused some controversy over the last forty years.[90]

Professor Boyce explained that –

> "There are a small number of people who do not believe in brain death…I do not think there is any scientific justification for saying brain death is not dead. The very fact that you cannot breathe without a machine would suggest to me that if you are not dead, you pretty much should be. What is more, we know if you follow these people the heart will stop within a period of hours anyway, so I thing that argument is well at the margins."[91]

However, some individuals felt very strongly about this issue and provided documentation supporting the idea that pain could still potentially be experienced by the donor and that in some rare cases recovery could occur.[92]

The David Hookes Foundation attempts to allay such fears by reminding people in their current brochures, that it is impossible to recover from brain death.[93] Indeed, Professor Bell stated that in relation to brain death, two points have been concluded –

> "…if you met the criteria for brain death on a single occasion you always met it and the second was that you never woke up and you always died. They are the only criteria in medicine I know that have never been shown to fail."[94]

Professor Bell highlighted one area that may need to be considered in the Tasmanian legislation and that is when death actually occurs. He believes

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[88] Newell, Christopher, AM, Associate Professor Medical Ethics, University of Tasmania, p. 2.
[89] Newell, op. cit., p. 3.
[90] Brain Death, "All in the Mind" Radio National transcript, program aired Sunday 23 June 2002
[91] Boyce, Transcript of Evidence, op. cit., p. 26.
[92] Donnelly, op. cit., p. 2.
[93] David Hookes Foundation brochure, op. cit., p. 6.
[94] Bell, op. cit., pp. 17-8.

that the time of death should be recorded as the time at which the first brain death test results are known, however, sometimes the Coroner requests it to be when the heart stops beating.[95]

Lack of Transplants in Tasmania and Compensation Issues

Mr Aaron Mackrill, a donor recipient and a registered nurse, believed that –

> "There are a few issues, especially for Tasmanians, in the fact that all organ transplants have to travel to the mainland. That is probably why the donation rate in Tasmania might be a bit lower, because we don't do the operations here in Tasmania. Possibly we do not get as much publicity as some of the mainland hospitals. Most people who live around the Alfred Hospital know that they do transplants there, so it is probably in the back of their minds."[96]

A related issue was the cost associated with donation from live donors. According to Ms Mackintosh of KHA –

> "…more needs to be done to make live donation more feasible, especially for kidneys. Transplant operations are not performed in Tasmania. Many donors remain out of pocket for expenses associated with their travel, accommodation and time off work. Establishing a live donor reimbursement scheme similar to what they have done in WA would assist potential donors on low incomes, as would a subsidy for lost wages when recuperating from surgery.[97]

To further support this claim, evidence in the written submission from KHA stated that the "United States, New Zealand, United Kingdom and several Canadian states all have compensation schemes in place that cover loss of earnings incurred through donation".[98]

In comparison between donation and dialysis, Ms Mackintosh stated –

> "Having in-hospital haemodialysis costs $82 000 per person per annum. Transplant recipients cost $10 000 per annum after their first year of having the operation so they are saving the health system a lot of money and the cost of dialysis in Australia is presently growing by $1million a week. It is a very expensive treatment but organ donations can significantly reduce that cost".[99]

Altruistic Donation/Directed Donation

Ms Sue Robertson commented on altruistic donation; an issue that may require legislative intervention. Such procedures have had guidelines devised

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[95] Bell, op. cit., p. 30.
[96] Mackrill, op. cit., pp.1-2.
[97] Mackintosh, op. cit., p. 50.
[98] Matthew, op. cit., p. 3.
[99] Mackintosh, op. cit., p. 50.

for them by hospitals in other states, including Western Australia, South Australia and New South Wales.

She explained that –

> "Under these guidelines [those involved in live donor donations] donations remain anonymous so that kidneys go to a best matched recipient and there are no costs or payments involved, which is illegal in Australia."[100]

She suggested that –

> "National guidelines and processes need to be developed to ensure that potential donors do not need to go overseas to fulfil their desires and similarly those on waiting lists do not feel they need to look outside Australia for a solution to their problem and that is happening."[101]

The donation landscape is constantly changing.[102] Dr Jose alluded to the fact that LifeGift had blocked altruistic donations from occurring four of five years ago, only for it to be happening in some hospitals in Australia such a short time later.

Some submissions suggested that restrictions on altruistic donation in the state may be forcing those who are desperate to look elsewhere. Dr Jose advised that he had given a Tasmanian man the contact details of a New South Wales physician in order for him to donate his kidney.[103]

Ms Michelle Eather, an altruistic kidney donor, related her experience of attempting to donate her kidney within Australia –

> "I contacted a number of hospitals around Australia to see how I could make a donation to a person on our waiting lists. Without exception, every single hospital refused my offer without consultation…Recently a number of Australian hospitals have adapted their guidelines governing donation to make an allowance for non-directed donors to come forward. Unfortunately the protocols for non-directed donation that have been implemented to date appear to be aimed towards discouraging rather than encouraging donors and appear to be based on a belief that if an individual wants to donate a kidney then there must be something wrong with them and if there is something wrong with them they should not be allowed to donate a kidney.
>
> The process is excessively long – 15-18 months – requires an intense commitment by the donor, is financially restrictive as there

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[100] Robertson, op. cit., p. 50.
[101] Robertson, op. cit., p. 50.
[102] Jose, op. cit., p. 35.
[103] Jose, ibid., p. 35.

> is no compensation whatsoever and the donor will be required to take substantial leave from their employment. All donations are carried out under strict anonymity. The donor has no choice who will receive their kidney and, ultimately, all of this is dependent upon the approval of an ethics committee… I made an informed choice to reject these options and instead chose to donate to a gentleman in the United States. I did so with the full knowledge of the facts and the risks associated with the surgery. I donated at a time that was right for me and to a person of my choosing."[104]

Ms Sue Robertson suggested that –

> "Altruistic donation is an area that needs thorough investigation. Another point which can be controversial is for live donors to have, not a payment for the kidney, but a case-by-case individual review of financial support for their lost earnings during the time they are incapacitated. They have relieved the burden on the health system by donating their kidney and they should not have to suffer any financial loss because of that."[105]

Ms Eather made the comment that –

> "It would be very easy to hear my submission and think that I am just one woman who chose to go on this journey. I am not. Currently there are more than 70 Australians registered on one web site alone to donate to American citizens. Another transplant occurred in the US just days ago and I personally am in contact with 23 individuals who wish to become kidney donors. Not one of them is prepared to donate in this country under our existing laws."[106]

This suggests that there are a number of consenting donors who are not being adequately catered for under the current legislative arrangement.

> "Sadly, I am also aware of a number of desperate Australians who are currently arranging their own transplants courtesy of the Indian and Philippines black market where a kidney can be obtained for as little as $2000. We would like to believe that this insidious trade is not happening. Well it is, every single week. Desperate Australians with no other treatment options will continue to take advantage of the poor and the under-privileged, and we have no way to regulate it. The trend towards patients finding their own donors and donors seeking their own recipients will only increase and the more established and unregulated the trade, the more likely it is that Australians will recognise their ability to financially benefit from donating their organs. It can and will happen."[107]

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[104] Eather, Ms Michelle, Transcript of Evidence, 2 October 2007, p. 21.
[105] Robertson, op. cit., p. 2.
[106] Eather, op. cit., p. 23.
[107] ibid., p. 24.

The fact that Tasmanian organ donation is linked to Victoria can potentially pose some problems. Dr Jose related a situation in Victoria whereby an auntie of someone on dialysis wanted to give their kidney to the relative, but she died in intensive care. When the family tried to direct the organ, they were not able to as the legislation would not allow directed organ donation after death and it had to go to the person deemed most deserving. Victoria is now investigating the relevant legislation.[108]

The current system distinguishes between directed donation before and after death along similar lines to property rights reserved in the body and any reform in this area is likely to incur opposition.[109] One development that may assist those awaiting donation is the paired organ swap, the first of which occurred in Western Australia in October 2007.[110] This innovation allows those people, who have willing donor relatives who are incompatible, to donate to the family member of another and vice versa.

Professor Bell was supportive of the NSW anonymous approach to altruistic donation. He estimated that 3 to 5 individuals a year may wish to donate organs in this way.[111] He saw this process as beneficial as it eliminated "external motives" regarding the donation process.[112] The Committee also noted that the National Health and Medical Research Council have recently released new ethical guidelines for directed donation.[113]

Conclusions

The Committee concludes that :

5. There is a need for an audit to fully measure the performance of the organ donation system in Tasmania.

6. In recent years the organ donation system has become complex and Tasmania needs an organ donation coordinator to assist in the identification of organ donors and management of the relevant protocols and procedures.

7. Due to the small population of Tasmania, organ donor conversion rates are a more meaningful measure of organ donor success than the more commonly used crude donor rate per million population.

8. Due to the short timeframes associated with successful organ retrieval and transplantation and the absence of organ transplantation surgery in Tasmania, there will be a lower number of realised donors of major organs. Only potential donors who die in specific circumstances

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[108] Jose, op. cit., p. 44.

[109] Griggs, Mr. Lynden, Senior Law Lecturer, Written Submission, p. 2.

[110] Kidney Health Australia "Life" 8 November 2007, http://www.kidney.org.au/LinkClick.aspx?fileticket=00iFRWaFrH8%3D&tabid=652&mid=1593 (accessed 19.3.08)

[111] Bell, op. cit., p. 28.

[112] Ibid., p. 28.

[113] Boadle, op. cit., p. 72.

resulting from brain death, rather than cardiovascular death, are likely to be realised.

9. In view of the state's population and the improved treatment and management of brain injury, it is unrealistic to expect any significant increase in the organ donation and conversion rates in Tasmania.

10. Data collection in Australia relating to the number of deaths of people awaiting organ transplantation is limited.

11. The definition of brain death and the possibility of recovery are issues of concern to some people. Tasmanian legislation regarding the actual time of death can be interpreted differently.

12. Current legislation imposes restrictions on altruistic/directed organ donation.

Impacts on Family Members and Education Issues Chapter 4

TERM OF REFERENCE (4)
The impact that uncertainty amongst family members regarding an individual's donation wishes has on their decision to allow organ donation and whether there is a reluctance on the part of doctors and family to proceed with donation even when the wishes of the donor were known to favour donation; and

TERM OF REFERENCE (5)
Whether there is a suitable education and promotion program in place to ensure the community appreciates the need for organ donation and understands the personal, social and financial benefits that donation and transplantation brings to the community.

Evidence suggested that even though the consent of the deceased alone may be sufficient to constitute consent for the donation of organs after death[114], in practice, family members were always consulted and their views respected.[115]

Dr Boadle said that he believed that this was –

> "…based on the philosophy that, whilst we would like to respect the wishes of the dead and whilst their consent really does allow us to override any family considerations, I think it is part of Australian culture that we tend to respect people's wishes where we can talk with them and if they have a strongly-held view.[116]

As family members are required to consent to donation, the importance of discussion about an individual's wishes cannot be under-estimated. Professor Boyce outlined that –

> "Several research studies in the past decade have confirmed that between 94 and 100% of Australians will respect the known wishes of their family members regarding organ donation. Even amongst those who are not personally in favour of organ donation, 94% report that they would support the known wish of family members to donate.
>
> If the wishes of a loved one are unknown, the likelihood of family support for donation drops dramatically. Of those next-of-kin who are personally in favour of organ donation 80% report that they would support donation by a deceased family member even if they did not know their wishes. But only 48% of those who are not personally intending to donate organs report a willingness to

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[114] Mackintosh, op. cit., pp. 48-9 .
[115] See discussion on actual consent in Chapter 2.
[116] Boadle, op. cit., p. 85.

> support donation by a family member if they do not know that that was their wish."[117]

The peace of mind of the decision-making family member could be eased through discussion of the topic. Senator Stephen Parry believed that, by knowing that–

> "…Dad wanted his organs donated…is a huge burden off your shoulders knowing you are complying with a dead man's wish. That is still a very strong issue in society today; you do not want to do anything against the wishes of a person who has just died. The first issue really is the lack of consent or known consent from the potential donor by the people who are left to make the decision. Secondly, it has to be made in a time of great emotional upheaval, stress, rushed, in the hospital setting, so it is very difficult for them to make that decision."[118]

It was suggested that some family members may be concerned about the physical appearance of their loved one after the donation surgery. Senator Parry sought to ease these concerns and advised that a donor's physical appearance is unchanged after organ donation.[119]

In an effort to ensure that wishes are followed, Ms Eather suggested that a "living will" may be an alternative. She related her experiences with the system in Virginia and the ability to make a legally binding agreement.[120]

Professional Influence

It was apparent from submissions to the inquiry that the there could be a marked impact on the donation process brought about by the professional involved in approaching the subject of donation with the family.

The manner in which the organ donation issue is approached is crucial. Mr Yeats, when relating his personal account, said that –

> "It was done in a very compassionate, delicate, sensitive way. Prior to this we had never given thought to organ donation because like a typical Australian, it happens to everybody else; it never happens to me. It is like road deaths; it is never going to happen to my kids…They approached us in a very tasteful way. They explained to us the procedure, what brain death meant, how they checked there was brain death, and we had absolutely no hesitation in donating organs. To this day, I am very glad we did because it really cushions the blow… I think the way in which a family of a potential donor is approached is so very important. You have to have a compassionate person doing it."[121]

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[117] Boyce, Written Submission, op. cit., p. 3.
[118] Parry, Senator Stephen, Transcript of Evidence, 5 October 2007, p. 26.
[119] Ibid., pp.22-3.
[120] Eather, op. cit., p. 27.
[121] Yeats, op. cit., p. 39.

Professor Boyce stated –

> "I do not think that we should not ask families because it is difficult for us health care professionals; I just do not think that is reasonable. We have to do a lot of things in life we would choose not to…I think it is a very special thing to do well. There is no doubt from the data that if you do it well your consent rate is infinitely higher because, as you can imagine, people making difficult decisions pick up on both verbal and non-verbal cues from people talking to them and pick up on a belief that this is a right and reasonable thing to do."[122]

Professor Bell acknowledged that the manner in which organ donation is approached is extremely important and that is why consultants, or supervised senior registrars, raise the topic.[123]

Evidence suggested that the issue would be a lot easier to discuss with families if there was greater knowledge of the processes involved. This would include educating both members of the medical profession and the community in general.

Professor Boyce stated that –

> "I think in the community education side of it we have to stop talking about knowledge and awareness and get people to change behaviour. The behavioural change is, 'Make a decision and tell your family'. Going on the register is okay; I think there will be a lot of people who do not want to be on a government database, frankly, but the real thing is to tell your family. There is little point keeping it in the privacy of your own mind and there is little point having a piece of paper you carry around in your wallet; you have to tell your loved ones."[124]

This view was re emphasized by Senator Parry who said that –

> "…generally most people are not aware of their legal rights in relation to organ donation. Your will is the last place you would put it because quite often, from a funeral director's perspective, the will is read after the body is in the ground, so it is absolutely too late to place it in a will. This is a useless avenue. The main thing is discussion, talking about it at home, talking about it with your loved ones… It happens usually around the bedside of the person whose organs have been ventilated for the purposes of potential harvesting."[125]

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[122] Boyce, Transcript of Evidence, op. cit., p. 22.
[123] Bell, op. cit., p. 23.
[124] Boyce, Transcript of Evidence, op.cit., p. 22.
[125] Parry, op. cit., p. 22.

There is still much that can be done to promote organ donation. Evidence suggests that the public is confused about issues surrounding organ donation, how to register their intention and the processes and probability of organ donation if they do.

Ms Mackintosh, suggested that this confusion could stem from the fact that –

> "… In the past Tasmanians have been urged to indicate their intention to be an organ donor on their licence by ticking a box. Many Tasmanians are still under the impression that, having done that, that is all they need to do."[126]

She further explained that –

> "The new system, whilst it has had some promotion, it has not been extensive enough and we would like to see more resources devoted to promotion and discussion about understanding what organ donation is. A lot of people think that they sign up to be a donor and when they die all their organs will be available for donation, but it is only a very small percentage of people who qualify to be a donor. They have to die under certain circumstances, be kept alive on a respirator, be pronounced clinically brain dead, so it only ends up being a very small number of people who become donors."[127]

When asked if they would accept a donated organ or do so for their son or daughter, the great majority of people agreed that they would. This should be contrasted and acknowledged as important. From an educational perspective it is believed that such an approach may increase the registration levels, as it forces the individual to consider the whole situation differently.

The current system sees many groups attempting to bring the issue of organ donation to the attention of the public. There are a myriad of different organisations which specialise in specific areas of organ donation in Australia and support their fundraising and awareness campaigns. Some of the most well known of these include the Zaidee's Rainbow Foundation and the David Hookes Foundation.

It is argued that a collective effort to create a cohesive and sustained approach to advertising is required. The end of Australians Donate and the start of the proposed cognitive committee, demonstrates an interesting comparison approach. It is believed that the restructure is necessary to ensure a sustained message is presented.

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[126] Mackintosh, op. cit., p. 47.

[127] Ibid., p. 50.

Educational Issues

Professional well informed staff to prompt discussion of organ donation and to ensure that opportunities are not lost, was suggested as a key area to increase rates of organ donation.

Evidence indicated that many health care professionals were uncomfortable with the issue of organ donation and that many young medical and nursing students are often only instructed to a limited extent during their degrees.[128]

Dr Reid suggested that –

> "There is a substantial proportion of cases where the people who should have been considered as potential organ donors just weren't. If you had someone on site who could educate intensivists and physicians, even if it got a few more organs per year, it would make a big difference to individuals. I think it would be a good idea. Educate the health professionals."[129]

It was suggested that education of these professionals could be facilitated through the use of an organ donation coordinator and further utilisation of the ADAPT course.

With regard to the sign up rates to become potential donors, education was again highlighted as a critical issue. It was argued that it needed to be consistent and involve a continuous message.[130] Professor Boyce suggested that –

> "We should treat our lower than desired organ donation performance as a typical public health issue. We wish to see a change in a health-related behaviour. We wish to see a system where whenever anyone dies in circumstances where organ donation is possible, their wishes regarding donation are known, these wishes are enabled by our healthcare systems and are supported by the family of the potential donor."[131]

He thought that this would be a good approach as –

> "Australia has the best performance in these public-heath initiatives. I do not think we have ever dealt with this as a public-heath initiative. Let us take it out of the hands of the clever technical people and say to the public health people, 'How do we make this happen?'…It needs to be funded in that way, though; it is not sixpence here and tuppence halfpenny there; these are major slip-slop-slap, 'Don't drink and drive. You're a bloody idiot'

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[128] Jose, op. cit., p. 38, Mackrill, op. cit., p. 9.
[129] Reid, op. cit., p. 7.
[130] See discussion in Chapter 3 to increase donor rates.
[131] Boyce, Written Submission, op. cit., p. 4.

> – type campaigns that go on continuously because it appears you need that level of reinforcement."[132]

His suggestion for a powerful advertising campaign would be to –

> "Think about the way we have done the slip, slop, slapping or the drinking and driving. Essentially they are thematic programs that run over time and are refreshed periodically. They use mass media and targets for particular demographics…"[133]

In addition, the Committee was fortunate to hear many personal accounts of organ donation and received many suggestions from those who had had experience in the area.

Mrs Nikki Nolan, the mother of an organ donor, suggested that the key was –

> "Education, education, education. There should not be an organ donor week; there should be an organ donor month and I think you should encourage families to have an organ donor Sunday lunch. When you are happy, have had a couple of wines, you say to yourself 'why not'.[134]

The majority of those who spoke suggested that organ donation had to be something that was commonly and openly addressed by families. University of Tasmania Law lecturer, Mr Lynden Griggs suggested that a change was needed to –

> "…lead to a cultural shift in society where organ donation is openly discussed amongst family members, with the wish to be an organ donor not coming as a surprise to the grieving relatives. Given the window of opportunity to successfully complete an organ donation is relatively short following the brain death of an individual, delays caused by well-meaning relatives would be significantly reduced."[135]

It was acknowledged in the submissions that previous advertising campaigns had been hampered by a lack of funding and therefore continuity and influence.[136] Mrs Nolan reflected that –

> "We were sitting down on the deck and I said, 'You have to get people to think, it is a bit like the Chinese water torture. You have stickers in the back of cars just to keep reminding you, just to keep it somewhere in your subconscious, not down the bottom, not where it is too hard to think about, but something that is gradually drip-fed into you."[137]

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[132] Boyce, Transcript of Evidence, op. cit., p. 23.
[133] Ibid., p. 30.
[134] Nolan, Mrs Nikki, Transcript of Evidence, 2 October 2007, p. 13.
[135] Griggs, Mr Lynden, Senior Lecturer in Law, University of Tasmania, Written Submission, p. 2.
[136] See submission of Australians Donate regarding their 6 million in funding.
[137] Nolan, op. cit., p. 11.

Many witnesses believed that greater exposure to advertising as well as an opportunity for discussion with people who had experienced the transplant process, would be beneficial.[138]

> "We need to be asking Australians how they can better promote their register in Tasmania because they have to undo what Tasmanians have learnt before. I think they need to generate a bit more discussion about the process of organ donation and what it means to people who have to go through it, and promote the awareness that families need to discuss the issue. I think that that is one area that they probably have promoted a little bit, but in terms of an overall package it needs to be a big national message and a sustained message."[139]

Education in schools was viewed as valuable in demystifying and explaining the organ donation process. Mr Mackrill suggested –

> "It may be worthwhile visiting schools and starting to educate the kids as well …You would probably aim it at high schools and colleges. I think the key thing is education, to educate the public and give them the facts and tell them that everything is fine."[140]

Other initiatives included sending out SMS messages[141] and access issues being addressed by placing extra forms in Service Tasmania shops and post offices, as well as including information on the back of registration stickers.[142]

Previous advertising and information campaigns were considered by some as too boring and that people would not have paid them much attention.[143] Mr Yeats suggested that a "well-accepted, high-profile person pushing for it within Tasmania" was required.[144]

Senator Parry thought that a key concern was that –

> "…there is overwhelming ignorance – people do not comprehend that less than 1 per cent of people are in a position to ever donate an organ. People think that if you die naturally in your sleep tonight and you are healthy, your organs can be harvested which, as you would now know, is totally incorrect. An education prong would have to be the first aspect, indicating to people that we need everyone to consent and do everything they possibly can to inform people in their family and people who will be making decisions post-death that it is such a rarity that you die in the right circumstances that your organs can be used for organ donation. I think that it is the greatest ignorance within the community and if

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[138] Gray, op. cit., p. 40.
[139] Mackintosh, op. cit., p. 61.
[140] Mackrill, op. cit., p. 2.
[141] Watchman, Ms Jacqualine, Transcript of Evidence, 5 October 2007, p. 34.
[142] Nolan, op. cit., p.18.
[143] Ibid., p. 12.
[144] Yeats, op. cit., p. 46.

> we can get that issue through first, I believe that is going to go a long way towards getting people to volunteer.

Mr Rudie Sypkes highlighted the importance of face to face contact –

> "Certainly in my view there is no better way than somebody individually talking one on one because then you can cover the bases well. It is a problem to get out there in the public arena, but I think there are great opportunities through organisations such as Rotary, Lions, Legacy and the different service groups…Certainly in my experience, once one of the family members has signed up it does not take long before the whole family sign up. Again, one of the big things in any marketing, I believe, is it is essential to tell your family what you are doing."[145]

He continued –

> "I think you raise awareness of it through the media. I am not convinced that you get signatures because of that increased awareness. My experience has shown that so much is from personal contact, a personal request, a personal suggestion. To promote the issue of organ donors in the media highlights and lifts the whole profile, as does an organ donor day. Then people are much more prone to be happy and sign up."[146]

In relation to education schemes, an overarching and continued message was considered necessary to ensure that individual state agencies did not create their own models, but rather one central one. Some witnesses believed that the previous LifeGift module aimed at high school students and the Australians Donate primary school program had proved ineffective.[147]

Conclusions

The Committee concludes that –

13. There is a need to demystify and normalise organ donation through education and awareness programs for health professionals, in schools and the community.

14. The consent of surviving family members is consistently sought by health professionals prior to organ retrieval.

15. When family members are aware of the wishes of their deceased relative regarding organ donation, they are more likely to consent.

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[145] Sypkes, Mr Rudie, Transcript of Evidence, 2 October 2007, p. 43.

[146] Ibid., p 46.

16. Organ donation awareness week has a role in promoting awareness of the need for and the benefits of organ donation. However, a more frequent and regular promotional program, addressed as a public health issue, would be more effective.

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Reid, Dr David, Specialist, Respiratory Medicine, Royal Hobart Hospital, Transcript of Evidence, 1 October 2007

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Roxon, The Hon. Nicola MP, Minister for Health and Ageing, “New national efforts to lift organ donation rates”, Media Release 17 February 2008

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Sypkes, Mr Rudie, Transcript of Evidence, 2 October 2007

Watchman, Ms Jacqualine, Transcript of Evidence, 5 October 2007

Wilkinson, Hon J., Hansard, 5 June 2007

Yeats, Mr John, Transcript of Evidence, 5 October 2007

List of Witnesses Appendix 1

Alessandrini, Dr Megan

Australia and New Zealand College of Anaesthetists

Bell, Clinical Professor Anthony

Booth, Faye

Christian Science Committee on Publication for Tasmania

David Hookes Foundation

Department of Health and Human Services

Donnelly, Laraine

Eather, Michelle

Gray, Andrew

Gray, Paul

Joint Faculty of Intensive Care Medicine, Victoria

Jones, Professor Robert

Jose, Dr Matthew

Kidney Health Australia (Tasmania)

LifeGift Victoria

Mackrill, Aaron

Markota, Mirko

National Organ Donation Collaborative

Nolan, Nikki

Parry, Senator Stephen

Reid, Dr David

Robertson, Sue

South Australian Department of Health

Sypkes, Rudie

Turner, Patricia

Victorian Health Department

Watchman, Jacqualine

Yeats, John and Joan

Written submissions taken into evidence

Appendix 2

Ambikapathy, Patmalar and Dr Arunasalam

Australians Donate

Christian Science Committee on Publication for Tasmania

Department of Health and Human Services

Gray, Andrew

Griggs, Lynden

Jose, Dr Matthew

Kidney Health Australia (Tasmania)

LifeGift Victoria

Morris, Don

Newell AM, Associate Professor Christopher

Roberts C A

Smith, Gary

Soutar, Shirena

Walker, Geoff

Watchman, Jacqualine

Documents taken into evidence

Appendix 3

Folder of documents regarding views on brain death and the terms of reference

Notes for the hearing

Four letters from recipients of organs

Service of Thanksgiving Booklet – Melbourne City

Brochure – Two Heads Two Lungs Inc Australia Lung Foundation

Application Forms to be Organ Donor

Hearing Notes

Australia and New Zealand Organ Donation Registry – 2007 Report

Speech to the Australian Parliament on Organ Donation – 7 February 2007

Letter to Editor – 26 June 2007 (The Advocate Newspaper)

Newspaper article – Peter Lyons – 19 July 2007

Project Forward, A National Initiative to Optimise Registration on the Organ Donor Register, 2nd November 2007

Australians Donate Conference Papers and Brochures

AHMAC Governance Review of the Organ and Tissue Sector – October 2007

Senior Officials' Committee – Governance for the Organ and Tissue Sector

Joint Report of the Department of Human Services and LifeGift, the Victorian Organ Donation Service, "Potential for Organ Donation in Victoria: An audit of hospital deaths", Helen Ingrid Opdam and William Silvester, Intensive Care Med (2004)

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LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

TUESDAY, 12 JUNE 2007

The Committee met at 2.02 pm in the Ante Chamber, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Order of Parliament :

The Order of the Parliament appointing the Committee dated 6 June 2007, having been circulated, was taken as read.

Election of the Chair :

Mr *Wilkinson* was elected Chair and took the Chair.

Business :

Resolved :

(a) That witnesses be heard under Statutory Declaration.

(b) That evidence be recorded verbatim unless otherwise ordered by the Committee.

(c) That advertisements be inserted in the early general news pages of the three daily Tasmanian newspapers on Saturday, 16 June 2007 and that receipt of written submissions be conditioned for closure on Friday, 10 August 2007. The draft advertisement, as amended, was agreed to.

(d) That the Secretary send invitations to make submissions to :

State Minister for Health
State Minister for Infrastructure
Federal Minister for Health
AMA
Australian and New Zealand Intensive Care Society
Organ Donation Australia – Mr *Wilkinson* to provide contact details

Right to Life
Civil Liberties organisation
Dr Christopher Newell – Ethics Society
Mrs *Rattray Wagner* to provide contact for people who have donated organs

Other Business :

Resolved, That –

- Members advise the Secretary of any further suggestions for invitations to make submissions.

- A press release be sent to all media next week advising of the Committee's establishment and request for submissions.

At 2.22 pm the Committee adjourned until Wednesday, 4 July 2007.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

WEDNESDAY, 4 JULY 2007

The Committee met at 10.40 am in the Ante Chamber, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Confirmation of Minutes :

The Minutes of the meeting held on Tuesday, 12 June 2007 were confirmed as a true and accurate record.

Correspondence :

Resolved, That the following correspondence be received –

- Email dated 22 June 2007 from the Office of Senator Stephen Parry advising that Senator Parry would be making verbal and written submission and requesting advice on the dates of hearings.
- Letter dated 25 June 2007 from Kidney Health Australia advising that the National Medical Director will be preparing a submission.

- Letter dated 27 June 2007 from the Ministerial Liaison and Support Section, Department of Health and Ageing acknowledging receipt of the invitation to participate in the inquiry.

Submissions :

Resolved, That the following submission be received –

(1) Lynden Griggs, Senior Lecturer in Law

Other Business :

Resolved, That –

- Invitations be sent to Sue Robertson, Unit Manager, Renal Unit, North West Regional Hospital, Paul and Andrew Gray and Fiona Coote.
- A media story regarding organ donors and the Committee be arranged for later in July.
- The Committee hear evidence from Organ Donation Australia first.

At 10.53 am the Committee adjourned until a date to be advised.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

WEDNESDAY, 5 SEPTEMBER 2007

The Committee met at 12.53 pm in Committee Room No. 3, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Confirmation of Minutes :

The Minutes of the meeting held on Wednesday, 4 July 2007 were confirmed as a true and accurate record.

Correspondence :

Resolved, That the following correspondence be received –

- Letter dated 27 July 2007 from the Australian Red Cross advising that a submission will be forwarded.
- Letter dated 2 August 2007 from Australians Donate advising that they would like to participate in the hearings in support of their submission.
- Letter dated 24 August 2007 from the Department of Health and Ageing providing information re Organ Donation in Australia.

Submissions :

Resolved, That the following submissions and requests be received –

(2) Paul Gray
(3) Sue Robertson – North West Renal Unit
(4) Mirko Markota
(5) Nikki Nolan
(6) Gary Smith
(7) Andrew Gray
(8) Kidney Health Australia
(9) Christian Science Committee on Publication for Tasmania
(10) Department of Health and Human Services
(11) Jacqualine Watchman
(12) Dr Matthew Jose
(13) Assoc. Prof. Christopher Newell AM
(14) C A Roberts
(15) Michelle Eather
(16) Senator Stephen Parry
(17) Shirena Soutar
(18) LIfeGift Victoria – Australian Red Cross Blood Service
(19) Australians Donate

Other Business :

Resolved, That –

- Contact Mr Rudie Sypkes inviting him to present verbal evidence to the Committee and inquire of him whether he can recommend any other individuals or organisations who would be of interest to the Committee.

- **Future program**
  That public hearings take place on:
  Monday, 1 October 2007 in Hobart
  Tuesday, 2 October 2007 in Hobart
  Wednesday, 3 October 2007 in Hobart
  Friday, 5 October 2007 in Burnie

- The Committee write to the New Zealand Parliament regarding their Committee inquiry.

At 1.12 pm the Committee adjourned until Monday, 1 October 2007.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

MONDAY, 1 OCTOBER 2007

The Committee met at 9.52 am in Committee Room No. 2, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Confirmation of Minutes :

The Minutes of the meeting held on Wednesday, 5 September 2007 were confirmed as a true and accurate record.

Requests to Give Verbal Evidence :

Resolved, That the following Requests be received –

(20) Rudie Sypkes
(21) Faye Booth
(22) John and Jane Yeats
(23) Dr David Reid
(24) Aaron Mackrill

Public Hearings :

DR DAVID REID was called, made the Statutory Declaration and was examined.

The witness withdrew.

ASSOCIATE PROFESSOR NEIL BOYCE on behalf of LifeGift Victoria, Australian Red Cross Blood Service, was called, made the Statutory Declaration and was examined.

The witness withdrew.

DR MATTHEW JOSE was called, made the Statutory Declaration and was examined.

The witness withdrew.

The Committee suspended at 12.55 o'clock pm.
The Committee resumed at 1.47 o'clock pm.

CAROLYN MACKINTOSH AND BERNIE FARRELL, on behalf of Kidney Health Australia, were called, made the Statutory Declaration and were examined.

The witnesses withdrew.

GRAHAM HARDING AND MARGARET CLARKE, on behalf of Christian Science Committee on Publication for Tasmania were called, made the Statutory Declaration and were examined.

The witnesses withdrew.

The Committee suspended at 3.02 o'clock pm.
The Committee resumed at 3.20 o'clock pm.

HELEN MULCAHY AND DR DAVID BOADLE, on behalf of the Department of Health and Human Services were called, made the Statutory Declaration and were examined.

The witnesses withdrew.

Other Business :

- The Chair advised the Committee that Christopher Newell did not wish to present verbal evidence, unless the Committee had specific questions of him.

Resolved, That –

- Aaron Mackrill be asked to give verbal evidence at 9.00 am on Wednesday, 3 October.

- The Committee discussed issues for inclusion in the Report.

At 4.53 pm the Committee adjourned until 8.45 am on Tuesday, 2 October 2007.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

TUESDAY, 2 OCTOBER 2007

The Committee met at 8.57 am in Committee Room No. 2, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Confirmation of Minutes :

The Minutes of the meeting held on Monday, 1 October 2007 were confirmed as a true and accurate record.

Public Hearings :

MS LARAINE DONNELLY was called, made the Statutory Declaration and was examined.

The witness withdrew.

MS NIKKI NOLAN, was called, made the Statutory Declaration and was examined.

The witness withdrew.

MS MICHELLE EATHER was called, made the Statutory Declaration and was examined.

The witness withdrew.

The Committee suspended at 10.40 o'clock am.
The Committee resumed at 10.45 o'clock am.

INSPECTOR PAUL GRAY was called, made the Statutory Declaration and was examined.

The witness withdrew.

MR ANDREW GRAY was called, made the Statutory Declaration and was examined.

The witness withdrew.

MR RUDIE SYPKES was called, made the Statutory Declaration and was examined.

The witness withdrew.

MS FAYE BOOTH was called, made the Statutory Declaration and was examined.

The witness withdrew.

Tabled Documents :

- Folder of documents regarding views on brain death and the terms of

reference (6)
- Notes for the hearing (6)
- Four letters from recipients of organs (5)
- Service of Thanksgiving Booklet – Melbourne City (5)
- Brochure – Two Heads Two Lungs Inc Australia Lung Foundation (20)
- Application Forms to be Organ Donor (20)

At 12.30 pm the Committee adjourned until 8.45 am on Wednesday, 3 October 2007.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

WEDNESDAY, 3 OCTOBER 2007

The Committee met at 9.00 am in Committee Room No. 2, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Public Hearings :

MR AARON MACKRILL was called, made the Statutory Declaration and was examined.

The witness withdrew.

Confirmation of Minutes :

The Minutes of the meeting held on Tuesday, 2 October 2007 were confirmed as a true and accurate record.
The witness withdrew.

At 9.35 am the Committee adjourned until 11.45 am on Friday, 5 October 2007 in Burnie.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

FRIDAY, 5 OCTOBER 2007

The Committee met at 11.45 am in the Library Tutorial Room, North West Regional Hospital, Burnie.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Confirmation of Minutes :

The Minutes of the meeting held on Wednesday, 3 October 2007 were confirmed as a true and accurate record.

Correspondence :

Resolved, That the following correspondence be received –

Email dated 2 October from David Carter providing suggestions to increase the number of organ donors.

Submissions :

Resolved, That the following Submissions be received –

(25) Geoff Walker
(26) Don Morris

Public Hearings :

MS SUE ROBERTSON was called, made the Statutory Declaration and was examined.

The witness withdrew.

Mr MIRKO MARKOTA was called, made the Statutory Declaration and was examined.

The witness withdrew.

MS PATRICIA TURNER was called, made the Statutory Declaration and was examined.

The witness withdrew.

The Committee suspended at 1.10 pm.
The Committee resumed at 2.17 pm.

SENATOR STEPHEN PARRY was called and was examined.

The witness withdrew.

MS JACQUALINE WATCHMAN was called, made the Statutory Declaration and was examined.

The witness withdrew.

MR JOHN AND MRS JOAN YEATS were called, made the Statutory Declaration and were examined.

The witnesses withdrew.

Tabled Documents :

- Hearing Notes (3)
- Australia and New Zealand Organ Donation Registry – 2007 Report (3)
- Speech to the Australian Parliament on Organ Donation – 7 February 2007 (16)
- Letter to Editor- 26 June 007 (The Advocate Newspaper) (16)
- Newspaper article – Peter Lyons – 19 July 2007 (16)

Future Program :

Resolved, That the Committee visit Victoria and possibly South Australia to meet with relevant stakeholders.

At 4.00 pm the Committee adjourned until a date to be determined.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

MONDAY, 26 NOVEMBER 2007

The Committee met at 8.35 am in the LifeGift Offices, 538 Swanston Street, Melbourne.

Members Present : Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Apologies : Ms *Forrest*

Meetings :

The Committee met with Associate Professor Neil Boyce, Executive Officer, LifeGift.

Assoc. Professor Boyce withdrew.

Confirmation of Minutes :

The Minutes of the meeting held on Friday, 5 October 2007 were confirmed as a true and accurate record.

Correspondence :

Resolved, That the following correspondence be received –

- Letter dated 5 October 2007 from Yael Cass, Assistant Secretary, Blood, Organ and Tissue Policy Branch, Department of Health and Ageing, Canberra clarifying issues regarding the Australian Organ Donor Register.

- Letter dated 31 October 2007 from the President, Legislative Council approving the Committee's travel.

- Letter dated 5 November 2007 from Australians Donate regarding new initiatives associated with organ donation and enclosing the National Organ Donation Collaborative DVD.

- Undated letter from Laraine Donnelly suggesting a DVD for educational purposes funded, monitored and promoted by Medicare.

Submission :

Resolved, That the following Submission be received –

(28) Mrs Patmalar Ambikapathy and Dr Arunasalam Ambikapathy

Document :

Resolved, That the following document be tabled –

- Project Forward, A National Initiative to Optimise Registration on the Organ Donor Register, 2nd November 2007

The Committee suspended at 10.30 am.
The Committee resumed at 11.05 am.

Meetings :

The Committee met with Dr William Silvester, Joint Faculty of Intensive Care Medicine.

Dr Silvester withdrew.

The Committee met with Dr Mark Buckland, Australia and New Zealand College of Anaesthetists.

Dr Buckland withdrew.

The Committee suspended at 12.30 pm.
The Committee resumed at 2.05 pm.

The Committee met with Mr Ashley Eccles, Senior Program Adviser, Blood and Pharmaceutical Programs, Victorian Health Department.

Mr Eccles withdrew.

At 3.45 pm the Committee adjourned until Tuesday, 27 November 2007.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

TUESDAY, 27 NOVEMBER 2007

The Committee met at 8.43 am in the Plaza Room, Parliament House, Adelaide.

Members Present : Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Apologies : Ms *Forrest*

Meetings :

The Committee met with representatives of the National Organ Donation Collaborative - Marcia Coleman and Terry Slater (Australians Donate), Dr Gerry O'Callaghan (Clinical Leader of the National Collaborative) and Kathy Hee (South Australian Organ Donation Agency).

Tabled Documents :

- Australians Donate Conference Papers and Brochures
- AHMAC Governance Review of the Organ and Tissue Sector – October 2007

- Senior Officials' Committee – Governance for the Organ and Tissue Sector

Messrs Coleman, Slater, O'Callaghan and Hee withdrew.

The Committee suspended at 10.50 am.
The Committee resumed at 11.00 am.

The Committee met via phone link with Mrs Robyn Hookes, David Hookes Foundation.

Mrs Hookes withdrew.

The Committee suspended at 11.50 am.
The Committee resumed at 12.05 pm.

The Committee met with Ms Sue Ireland, Manager, Blood, Organ and Tissue Programs, South Australian Department of Health.

Ms Ireland withdrew.

At 1.07 pm the Committee adjourned until a date to be advised.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

WEDNESDAY, 30 JANUARY 2008

The Committee met at 10.58 am in Committee Room No 2, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Confirmation of Minutes :

The Minutes of the meetings held on Monday, 27 and Tuesday 27 November 2007 were confirmed as a true and accurate record.

Correspondence :

Resolved, That the following correspondence be received and acknowledged –

Email dated 3 December from Jacqualine Watchman providing suggestions about educating teenagers about organ donation.

Additional Information :

Resolved, That the following additional information be received –

- Joint Report of the Department of Human Services and LifeGift, the Victorian Organ Donation Service, "Potential for Organ Donation in Victoria: An audit of hospital deaths", May 2005 (18).
- "Identifying the potential organ donor: an audit of hospital deaths", Helen Ingrid Opdam and William Silvester, Intensive Care Med (2004) (18).
- "Potential for organ donation in Victoria: an audit of hospital deaths", Helen I Opdam and William Silvester, MJA, Volume 185 Number 5, 4 September 2006 (18).

Meeting :

PROFESSOR ROBERT JONES met with the Committee via phonelink.

Other Business :

The Committee requested the Secretary to follow up the release of the Commonwealth Government's report on organ donation.

At 12.15 pm the Committee adjourned until Thursday, 14 February 2008.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

THURSDAY, 14 FEBRUARY 2008

The Committee met at 11.23 am in Committee Room No. 2, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner* and Mr *Wilkinson.*

Confirmation of Minutes :

The Minutes of the meeting held on Wednesday, 30 January 2008 were confirmed as a true and accurate record.

Public Hearings :

DR MEGAN ALESSANDRINI was called, made the Statutory Declaration and was examined.

The witness withdrew.

The Committee suspended at 12.25 pm.
The Committee resumed at 12.30 pm.

PROFESSOR ANTHONY BELL was called, made the Statutory Declaration and was examined.

The witness withdrew.

Other Business :

The Committee requested the Secretary to provide all Members with a copy of the National Collaborative Report when released.

At 1.30 pm the Committee adjourned until a date to be advised.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

THURSDAY, 3 APRIL 2008

The Committee met at 9.10 am in Committee Room No. 2, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mr *Harriss*, Mrs *Rattray-Wagner*

Order of Parliament :

The Order of the Parliament appointing the Committee dated 4 March 2008, having been circulated, was taken as read.

Election of the Chair :

Mr *Wilkinson* was elected Chair.

Resolved, that *Ms Forrest* take the Chair.

Confirmation of Minutes :

The Minutes of the meeting held on Thursday, 14 February 2008 were confirmed as a true and accurate record.

Draft Report :

The Committee considered issues in Draft Report No. 1 (26 March 2008).

At 10.38 am the Committee adjourned until a date to be advised.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

TUESDAY, 20 MAY 2008

The Committee met at 11.05 am in Committee Room No. 3, Parliament House, Hobart.

Members Present : Ms *Forrest*, Mrs *Rattray-Wagner, Mr Wilkinson*

Confirmation of Minutes :

The Minutes of the meeting held on Thursday, 3 April 2008 were confirmed as a true and accurate record.

Draft Report :

The Committee considered issues of Draft Report (as at 23 April 2008).

Adjournment

At 2.00 pm the Committee adjourned until a date to be advised.

LEGISLATIVE COUNCIL SELECT COMMITTEE

ORGAN DONATION

MINUTES

TUESDAY, 10 JUNE 2008

The Committee met at 11.07 am in Committee Room No. 3, Parliament House, Hobart.

Members Present : Ms *Forrest*, *Mr Harriss*, Mrs *Rattray-Wagner, Mr Wilkinson*

Confirmation of Minutes :

The Minutes of the meeting held on Tuesday, 20 May 2008 were confirmed as a true and accurate record.

Draft Report :

The Committee considered Draft Report (as at 23 May 2008), page by page.

Resolved, That the report be agreed to, with minor amendment.

Other Business :

Resolved, That –

- The Chair sign the final report and minutes.
- The Report be tabled in the Legislative Council on Wednesday, 11 June at 11 am.
- A media release be prepared and provided to Members for consideration, prior to its release.
- A media conference be held in the Media Room at 1.00 pm on Wednesday, 11 June and that all Members of the Committee attend.

At 11.45 am the Committee adjourned *sine die*.