

Report No 16, July 1999

**Review of the Transplantation and Anatomy Amendment Bill 1998**

LEGISLATIVE ASSEMBLY OF QUEENSLAND

**LEGAL, CONSTITUTIONAL AND ADMINISTRATIVE REVIEW COMMITTEE**

**Review of the Transplantation and Anatomy Amendment Bill 1998**

**July 1999**

**Report No 16**

## LEGAL, CONSTITUTIONAL AND ADMINISTRATIVE REVIEW COMMITTEE

<b>REPORTS</b>		<b>DATE TABLED</b>
1.	Annual report 1995-96	8 August 1996
2.	Report on matters pertaining to the Electoral Commission of Queensland	8 August 1996
3.	Review of the Referendums Bill 1996	14 November 1996
4.	Truth in political advertising	3 December 1996
5.	Report on the Electoral Amendment Bill 1996	20 March 1997
6.	Report on the study tour relating to the preservation and enhancement of individuals' rights and freedoms and to privacy (31 March 1997—14 April 1997)	1 October 1997
7.	Annual report 1996-97	30 October 1997
8.	The Criminal Law (Sex Offenders Reporting) Bill 1997	25 February 1998
9.	Privacy in Queensland	9 April 1998
10.	Consolidation of the Queensland Constitution - Interim report	19 May 1998
11.	Annual report 1997-98	26 August 1998
12.	The preservation and enhancement of individuals' rights and freedoms in Queensland: Should Queensland adopt a bill of rights?	18 November 1998
13.	Consolidation of the Queensland Constitution: Final Report	28 April 1999
14.	Review of the <i>Report of the Strategic Review of the Queensland Ombudsman</i> (Parliamentary Commissioner for Administrative Investigations)	15 July 1999
15.	Report on a study tour of New Zealand regarding freedom of information and other matters: From 31 May to 4 June 1999	20 July 1999
<b>ISSUES PAPERS</b>		<b>DATE TABLED</b>
1.	Truth in political advertising	11 July 1996
2.	Privacy in Queensland	4 June 1997
3.	The preservation and enhancement of individuals' rights and freedoms: Should Queensland adopt a bill of rights?	1 October 1997
<b>INFORMATION PAPERS</b>		<b>DATE TABLED</b>
1.	Upper Houses	27 November 1997

Copies of this report and other LCARC publications are available on the Internet via Queensland Parliament's home page at <[www.parliament.qld.gov.au/committees/legalrev.htm](http://www.parliament.qld.gov.au/committees/legalrev.htm)>.

The committee's contact details are:

Legal, Constitutional and Administrative Review Committee  
Parliament House  
George Street, Brisbane, Qld, 4000.  
Tel: (07) 3406 7307  
Fax: (07) 3406 7070  
Email: [lcarc@parliament.qld.gov.au](mailto:lcarc@parliament.qld.gov.au)

# LEGAL, CONSTITUTIONAL AND ADMINISTRATIVE REVIEW COMMITTEE

## 49<sup>TH</sup> PARLIAMENT

CHAIR:	Mr Gary Fenlon MLA, Member for Greenslopes
DEPUTY CHAIR:	Mrs Judy Gamin MLA, Member for Burleigh
MEMBERS:	Mr Denver Beanland MLA, Member for Indooroopilly
	Ms Desley Boyle MLA, Member for Cairns
	Dr Peter Prenzler MLA, Member for Lockyer*
	Mr Geoff Wilson MLA, Member for Ferny Grove
RESEARCH DIRECTOR:	Ms Kerryn Newton
PRINCIPAL RESEARCH OFFICER:	Mr David Thannhauser
EXECUTIVE ASSISTANT:	Ms Tania Jackman

\* Dr Prenzler was appointed to the committee on 11 November 1998 having replaced Mr Charles Rappolt whose resignation from Parliament was received by the Speaker of the Legislative Assembly on 4 November 1998.

## **CHAIR'S FOREWORD**

Queensland's community has embraced blood donation for many years as a means of giving the precious gift of life or quality of life to others. Now there is a need for our community to similarly embrace organ and tissue donation so that even more individuals may have their life extended or enhanced via the chances now afforded by medical technology.

That chance of life and better health for many people who benefit from organ transplantation is, in practice, possible through the family of a deceased person being satisfied that it was the wish of the deceased person to generously donate his/her organs and thereby authorising the donation.

While the Member for Thuringowa must be commended for his good intention in bringing the bill before the House, the committee does not believe that its implementation would enhance the donation process. In fact, the committee believes that the proposal, if implemented, may have a negative impact upon donor rates.

The bill attempts to give legal effect to an organ donor notation on a driver's licence, thereby making the licence holder's election binding and removing the need to seek consent from the deceased's next-of-kin.

However, that standard practice in hospitals of always consulting with the potential donor's next-of-kin means that if consent is refused, organ removal does not proceed. This is the case even if the deceased had consented fully in writing to becoming a donor on their death. There are strong ethical and practical reasons for this.

Community acceptance of organ donation has built over the last 30 years via a sensitive escalation of community awareness. Taking the organs of a loved one against the family's wishes will only hinder, not assist donation rates.

For these reasons the committee cannot endorse the bill.

However, other ways in which organ donation rates can be improved are considered in this report. As well as increasing awareness of organ donation by hospital staff and in the community, a major hurdle to donor identification is access to the licence database by the right people.

In essence, increasing organ donation is a matter for each of us as individuals and for families. It is a matter for individuals to make our decision about organ donation, and to choose how to best communicate this decision to our families.

On behalf of the committee, I would like to thank those who made submissions to and met with the committee. Also I thank the committee's staff, Ms Kerry Newton (Research Director), Mr David Thannhauser (Principal Research Officer), and Ms Tania Jackman (Executive Assistant) for their assistance throughout this review.

Finally, I thank my fellow committee members for their continuing hard work and dedication in ensuring that the committee fulfils its responsibilities.

Gary Fenlon MLA  
**Chair**

July 1999

## SUMMARY OF RECOMMENDATIONS

### **Recommendation 1**.....24

The committee recommends that the Parliament not support the Transplantation and Anatomy Amendment Bill 1998 in its current form.

### **Recommendation 2**.....25

The committee recommends that the Minister for Health, as the minister responsible for the *Transplantation and Anatomy Act 1979* (Qld), consider reviewing Part 3 of the Act (Donations of tissue after death) with the aim of establishing whether those provisions should be amended to more accurately reflect current practice in relation to organ donation and transplantation. Given the relative uniformity of these provisions in Australia (and given the desirability of maintaining that uniformity), this is a matter which the minister might wish to raise at an appropriate Australian Health Ministers' forum.

### **Recommendation 3**.....30

The committee supports the efforts of Australians Donate and Queenslanders Donate to increase education and awareness about organ donation both in the community and in hospitals. In particular, the committee supports the emphasis on educating people about the importance of communicating their decision to be a donor with their family. The conduct of periodic surveys will assist in measuring the effectiveness of these efforts.

The committee recommends that the Minister for Health consider the appropriateness and feasibility of appointing (as part of Queenslanders Donate) an organ donor advocate to further develop and promote education and awareness strategies regarding organ donation in the Queensland community.

To assist people in recording their decision to be a donor, the committee recommends that the Attorney-General, as the Minister responsible for the *Powers of Attorney Act 1998* (Qld), investigate amending that Act so as to allow people to record a wish to be an organ donor after their death in an advance health directive.

### **Recommendation 4**.....33

The committee recommends that Queensland Health (continue to) liaise with Queensland Transport (and Australians Donate) about utilising the driver's licence application and renewal process to provide people with information about organ and tissue donation. This information should encourage people to communicate their decision to be an organ donor with their family and be such that it gives the potential donor's next-of-kin confidence that the potential donor has made a well-informed or considered decision about organ donation. Where appropriate, changes should be made to the *Traffic Regulations 1962* and current administrative procedures to achieve this.

In addition, the committee recommends that the Minister for Transport amend the *Traffic Regulations 1962* to provide licence holders with an express statutory right to require amendment of the donor consent notation on their driver's licence at any time.

**Recommendation 5**.....36

The committee recommends that immediate steps be taken to overcome the restrictions which currently prevent access to the donor information on the Queensland driver’s licence database by those involved in organ donation.

In this regard the committee notes that Queensland Health has been negotiating with Queensland Transport to amend the current driver’s licence application/renewal form to include a question asking people who do consent to a donor notation being recorded on their driver’s licence to also consent to Queensland Transport providing that information to Queensland Health.

The committee urges the Minister for Transport and the Minister for Health to expedite moves to enable full use of this valuable data.

**Recommendation 6**.....38

The committee recommends that Queensland Health attempt to ascertain the viability of the Australians Donate proposal to establish a national donor database and support that proposal should Queensland Health consider it viable. (In this regard the committee notes that Queensland Health is represented on the National Council of Australians Donate.)

# CONTENTS

PAGE NO.

---

<b>1. INTRODUCTION</b> .....	<b>1</b>
1.1 THE INQUIRY PROCESS .....	1
1.2 THE PURPOSE OF THE BILL .....	2
1.3 SCRUTINY OF LEGISLATION COMMITTEE COMMENTS ON THE BILL.....	3
1.4 THIS REPORT .....	3
<b>2. ORGAN DONATION AND TRANSPLANTATION</b> .....	<b>4</b>
2.1 THE INTRODUCTION OF (UNIFORM) TRANSPLANTATION LEGISLATION.....	4
2.2 THE ORGAN DONATION PROCESS .....	5
2.2.1 Certification of 'death' .....	5
2.2.2 Authority to remove tissue or organs—the law and practice.....	5
2.2.3 Medical suitability.....	8
2.3 AUSTRALIA'S AND QUEENSLAND'S DONOR RATE.....	9
2.4 WHY PEOPLE DO/DO NOT DONATE .....	9
2.5 RECORDING DONOR INTENTION .....	10
2.5.1 The use of drivers' licences.....	10
2.5.2 Other ways to record donor intention.....	11
<b>3. WAYS TO INCREASE ORGAN DONATION</b> .....	<b>12</b>
3.1 THE SPANISH MODEL .....	12
3.2 THE US MODEL .....	13
3.3 THE SOUTH AUSTRALIAN MODEL .....	14
3.4 AUSTRALIANS DONATE.....	15
3.5 QUEENSLANDERS DONATE .....	15
<b>4. SHOULD THE BILL BE SUPPORTED?</b> .....	<b>18</b>
4.1 EVALUATION OF THE BILL.....	18
4.1.1 Issues raised in public consultation .....	18
4.1.2 Committee analysis and comment .....	22
4.1.3 Committee recommendation 1.....	24
4.2 A REVIEW OF THE <i>TRANSPLANTATION AND ANATOMY ACT</i> ? .....	24
4.2.1 Committee recommendation 2.....	25
<b>5. SPECIFIC MEASURES TO INCREASE THE NUMBER OF ORGAN DONORS IN QUEENSLAND</b> .....	<b>26</b>
5.1 A COORDINATED APPROACH TO ORGAN DONATION .....	26
5.2 RAISING AWARENESS ABOUT ORGAN DONATION .....	27
5.2.1 Committee recommendation 3.....	30
5.3 ENSURING A PERSON'S INFORMED DECISION REGARDING DONATION .....	31
5.3.1 Committee recommendation 4.....	33
5.4 IMPROVING ACCESS TO DRIVER'S LICENCE ORGAN DONATION DATA.....	34
5.4.1 Committee recommendation 5.....	36
5.5 ESTABLISHING A NATIONAL DONOR DATABASE.....	37
5.5.1 Committee recommendation 6.....	38
5.6 ESTABLISHING/MAINTAINING SUPPORT PROGRAMS FOR DONORS' FAMILIES.....	38
5.6.1 Committee observation.....	39
<b>6. CONCLUSION</b> .....	<b>40</b>



## 1. INTRODUCTION

The role of the Legal, Constitutional and Administrative Review Committee ('the committee' or 'LCARC') is to deal with issues within its areas of responsibility, namely, constitutional reform, electoral reform, administrative review reform and legal reform. In addition, the committee is to deal with an issue referred to it by the Legislative Assembly whether or not that matter is within its areas of responsibility.<sup>1</sup>

On 10 November 1998, Mr Ken Turner MLA (Member for Thuringowa) introduced into the Legislative Assembly a private member's bill, the Transplantation and Anatomy Amendment Bill 1998 ('the bill'). On 28 April 1999, following the second reading debate, the Assembly resolved that the bill be referred to the committee for 'consideration and report back to the House by 1 August 1999'.

### 1.1 THE INQUIRY PROCESS

On 5 May 1999, the committee called for public submissions on the bill in *The Courier-Mail*. In addition, the committee directly wrote to approximately 290 persons and organisations that it identified as having an interest in the bill. Organisations and persons approached by the committee included hospitals and medical staff involved in organ donation, religious and community groups, relevant government departments and agencies including various district health services, donor support groups, nursing and medical associations, medical research organisations, all state and federal health and transport ministers, and various Queensland legal institutions and professional bodies.

Submissions closed on 11 June 1999, although the committee continued to accept submissions well past that date. The committee received 53 submissions to its inquiry. A list of those who made submissions to the committee's inquiry appears as **Appendix A**.

On 30 June 1999, the committee tabled the non-confidential submissions that it received to that date<sup>2</sup> and advised the authors of all submissions that the committee would receive any additional comments that they might have (perhaps as a result of reading the tabled submissions) until 16 July 1999.

In addition:

- on 5 May 1999, the chair of the committee took an opportunity to visit Adelaide to meet with Professor Geoffrey Dahlenburg, Director of the South Australian Organ Donation Agency, and Mr Bruce Lindsay, National Director of Australians Donate;<sup>3</sup>
- on 27 May 1999, the committee received a briefing regarding issues relevant to the committee's inquiry from the Hon Wendy Edmond MLA (Minister for Health), Ms Tina Cooper (Manager, Queenslanders Donate<sup>4</sup>), Mr Graham Hyde (Manager, Bayside District Health Service and Queensland representative on the National Council of Australians Donate), Ms Katrina Horsley (Principal Policy Officer, Queensland Health) and Dr Diana Lange (Chief Health Officer, Queensland Health); and
- on 4 June 1999, whilst in New Zealand on a study tour primarily related to the committee's current review of Queensland's freedom of information legislation, the committee met with specialists involved in organ donation and transplantation in New Zealand.

---

<sup>1</sup> *Parliamentary Committees Act 1995*, s 8(1) and (2), and s 9.

<sup>2</sup> Some further non-confidential submissions received after that date were tabled on 13 July 1999.

<sup>3</sup> Both of these organisations are discussed further in chapter 3.

<sup>4</sup> Queenslanders Donate is discussed further in chapter 3.

## 1.2 THE PURPOSE OF THE BILL

The primary aim of the bill is to increase the number of cadaveric (or deceased) organ (and tissue) donors in Queensland.<sup>5</sup>

In his second reading speech, the Member for Thuringowa noted that, despite having one of the best transplant success rates in the world, Australia has the lowest rate of organ donation in the western world. Queensland, the member stated, like the rest of Australia suffers from a shortage of organs available for transplant, allowing 20% of patients on organ donation waiting lists to die before an organ donor becomes available.<sup>6</sup> Hence, the Member for Thuringowa stressed it was extremely important for Queensland to introduce a model to increase the number of organ donors so as to ensure that as few as possible potential donors are missed.

To 'help solve this problem in the immediate future', the bill seeks to 'give legal effect' to the donor consent notation which Queensland drivers can have recorded on their licences. The Member for Thuringowa stated that, at present, a donor consent notation on a driver's licence has 'no legal standing and, in the past, relatives and other persons have successfully stopped the organ donation process'.<sup>7</sup>

In other words, the bill seeks to make a licence holder's election regarding organ donation binding and remove the need for hospital staff to consult with the deceased's next-of-kin to ensure that they have no objection to the removal of tissue or organs from the deceased. (The circumstances in which hospital staff must or, in practice, do consult with the deceased's next-of-kin is explained further in chapter 2 of this report.)

The bill attempts to do this by amending the *Transplantation and Anatomy Act 1979* (Qld) ('the Act'). This Act authorises the use of a deceased person's organs and tissue for transplant and related purposes in stipulated circumstances. Under s 22(6) (*Authority to remove tissue where body of deceased in a hospital*) and s 23(3) (*Authority to remove tissue where body of deceased not in hospital*) of the Act, these circumstances include:

*Where a deceased person, during his or her lifetime, by signed writing consented to the removal after death of tissue from his or her body for any of the purposes referred to in subsection (1) and the consent had not been revoked by the deceased person, the removal of tissue from the body of the deceased person in accordance with the consent for any of those purposes is hereby authorised.*<sup>8</sup>

The bill seeks to achieve its stated objective by deeming that the donor consent notation on a Queensland driver's licence is 'signed writing' for the purposes of these subsections. Specifically, the bill proposes to insert a new s 25A into the *Transplantation and Anatomy Act* to provide:

*25A.(1) This section applies if a deceased adult's Queensland driver's licence in force at the time of the person's death indicates the person has consented to be a donor.*

---

<sup>5</sup> Mr K Turner MLA, Transplantation and Anatomy Amendment Bill 1998, *Queensland Parliamentary Debates*, Second Reading Speech, 10 November 1998, pp 2818-2819. An explanatory note did not accompany the bill, a matter on which the Scrutiny Committee made adverse comment when it scrutinised the bill. The bill only concerns cadaveric donors because it seeks to amend sections of the *Transplantation and Anatomy Act 1979* which only relate to the removal of tissue from a deceased person. The definition of tissue in the *Transplantation and Anatomy Act 1979*, s 4 includes an organ.

<sup>6</sup> Other sources cite different figures. See chapter 2.

<sup>7</sup> Ibid, p 2819. Crown Law advice confirms that a donor consent notation on a driver's licence is not sufficient for the purposes of the *Transplantation and Anatomy Act 1979*, s 22(6). See the discussion in section 2.2.2.

<sup>8</sup> The purposes in subsection (1) are: 'the transplantation of tissue to the body of a living person'; or 'using the tissue for therapeutic purposes or for other medical or scientific purposes'.

(2) For sections 22(6) and 23(3), the licence is taken to be signed writing by the person consenting to the removal after death of tissue from the person's body for any of the purposes mentioned in sections 22(1) and 23(1).

(3) Subsection (2) is effective for section 22(6) or 23(3) only in so far as the person relying on subsection (2) has no reason to believe the indication is incorrect or the consent has been withdrawn.

(4) In this section—

“*Queensland driver's licence*” means a driver's licence issued under the Traffic Act 1949.<sup>9</sup>

Therefore, the bill contains some safeguards in that the licence must be in force at the time of the person's death and the person relying on the provision must not have reason to believe the indication is incorrect or the consent has been withdrawn.<sup>10</sup>

### 1.3 SCRUTINY OF LEGISLATION COMMITTEE COMMENTS ON THE BILL

In its scrutiny of the bill, the Scrutiny of Legislation Committee of the Queensland Parliament recommended that if the bill is passed by Parliament:

- the *Traffic Regulations 1962* should be amended to provide licence holders with an express statutory right to require amendment of the ‘donor consent’ notation on their driver's licence either because it is incorrect or because they have changed their mind on the matter since their licence was issued;<sup>11</sup> and
- the *Traffic Regulations 1962* and current administrative practices be reviewed in order to ensure that applicants for drivers' licences are adequately informed of the implications of their decision concerning organ donation, and that their decision is made and recorded in a suitably formal manner.

The Scrutiny of Legislation Committee also considered that there would be merit in the current form of driver's licence cards being amended to state the licence holder's consent (or non-consent) more formally than at present.<sup>12</sup>

The Member for Thuringowa responded to the Scrutiny of Legislation Committee that he agreed with all three recommendations.<sup>13</sup>

### 1.4 THIS REPORT

This report summarises the committee's consideration of the bill.

The information regarding organ donation in chapters 2 and 3 is essential background to understanding the organ donation process in practice and the committee's ultimate position on the bill. In chapter 4, the committee draws together its analysis of the bill as informed by public consultation, its meetings and the background information in chapters 2 and 3, and comes to a position on the bill. In chapter 5, the committee considers, and makes specific recommendations about, alternative ways in which the bill's objective might be achieved.

---

<sup>9</sup> Transplantation and Anatomy Amendment Bill 1998, clause 3.

<sup>10</sup> The committee comments on the effect of the latter safeguard in chapter 4.

<sup>11</sup> Driver's licences may be issued for terms of up to ten years: *Traffic Act 1949*, s 14(6).

<sup>12</sup> Scrutiny of Legislation Committee, *Alert Digest*, No 10 of 1998, tabled 17 November 1998, p 7.

<sup>13</sup> Scrutiny of Legislation Committee, *Alert Digest*, No 1 of 1999, tabled 2 March 1999, p 65.

## 2. ORGAN DONATION AND TRANSPLANTATION

Advances in medical technology have meant an increase in the types of organs and tissue capable of transplantation since the first transplant of a cadaveric donor organ in Australia in 1963.<sup>14</sup> Organs which can now be transplanted include the heart, lungs, liver, kidney and pancreas. Types of tissue used in transplantation include corneas, heart valves, skin, bones and bone marrow.<sup>15</sup>

The Member for Thuringowa notes that Australia has one of the best transplant success rates in the world. Australians Donate advises that since 1965 there have been more than 28 000 transplants performed in Australia.<sup>16</sup> The organs from one donor can benefit up to nine or more people, and one tissue donor can assist up to 32 recipients.<sup>17</sup> For many people with life threatening illnesses, organ or tissue transplantation can provide the best chance of preserving or improving quality of life.<sup>18</sup>

However, each year a number of Australians on transplantation waiting lists die before a suitable donor is found.<sup>19</sup> In particular, there is a need to address *organ* donation rates. Donation rates for *tissue* comes closer to meeting demand, which means shorter waiting periods.<sup>20</sup>

### 2.1 THE INTRODUCTION OF (UNIFORM) TRANSPLANTATION LEGISLATION

In 1977, the Australian Law Reform Commission (ALRC) reported on a wide-ranging inquiry into the law and practice of organ and tissue donation and transplantation in Australia.<sup>21</sup> This inquiry exposed the inadequacy of the common law in regulating a number of matters in this area. In particular, it was apparent that ‘death’ needed to be defined to include brain death in order to avoid the possibility of leaving transplant doctors open to criminal prosecution.

In order to regulate the area (and remove it completely from the common law) the ALRC recommended that relatively uniform legislation be introduced throughout Australia to provide for the removal of human organs and tissue and to create a statutory definition of brain death. Hence the introduction of Queensland’s *Transplantation and Anatomy Act* in 1979.

At the time of the ALRC’s inquiry, the shortage of organ donors was a major concern and the ALRC wanted to ensure that there were no unnecessary impediments to those seeking transplants. However, the ALRC also recognised that regard had to be given to the individuals’ wishes (and the wishes of their relatives) regarding the use of their organs and tissue after death. The ALRC ultimately recommended that a competent adult should have the right to give their body—or any part of it—for transplantation and that their wishes should be paramount; that is, no person (except the coroner in relevant cases) should have the power to overrule the decision. The ALRC also

---

<sup>14</sup> R Easten, *A question of consent? The Transplantation and Anatomy Amendment Bill 1998*, Research Bulletin 1/99, Queensland Parliamentary Library, Brisbane, February 1999, p 7. Readers are commended to this informative research bulletin for further information about organ donation and transplantation.

<sup>15</sup> ACCORD website <<http://www.span.com.au/span/accord/donate.html>> downloaded on 14 July 1999.

<sup>16</sup> Australians Donate correct the private member’s figures in this regard: submission dated 9 June 1999, p 2.

<sup>17</sup> ACCORD website <<http://www.span.com.au/span/accord/donate.html>> downloaded on 14 July 1999.

<sup>18</sup> Queensland Health submission dated 22 June 1999, p 4.

<sup>19</sup> Both the private member and Queensland Health state that each year 20% of Australians on organ transplant waiting lists die before a suitable organ donor is found. (Queensland Health submission dated 22 June 1999, p 4.) Australians Donate says that it can find no evidence to support this and that in 1998 the total number of patients who died awaiting solid organ transplantation was 94 while the average number on the waiting list was 1711, which translates to 5.5%: submission dated 9 June 1999, p 2. The ACCORD website (noted above) and the NSW Red Cross website (<[http://www.organ.redcross.org.au/f\\_stats.html](http://www.organ.redcross.org.au/f_stats.html)> downloaded on 21 July 1999) state that 15% of those awaiting a heart, lung or liver will die before a transplant becomes available.

<sup>20</sup> Australians Donate submission dated 9 June 1999, p 1.

<sup>21</sup> Australian Law Reform Commission (ALRC), *Human tissue transplants*, report no 7, AGPS, Canberra, 1977.

recommended that this wish should be able to be expressed orally or in writing signed by the donor and that the donor should be able to revoke the wish at any time until their death.<sup>22</sup>

The ALRC's recommendations in this regard are reflected in the provisions of Queensland's *Transplantation and Anatomy Act* discussed below in this chapter and again in chapter 4.

## 2.2 THE ORGAN DONATION PROCESS

In Queensland (as in all Australian states), people of sound mind may, during their lifetime, elect to become an organ and/or tissue donor upon their death.<sup>23</sup> However, in essence three criteria must be fulfilled in order for a person to be a cadaveric organ donor.

### 2.2.1 Certification of 'death'

'Death' is defined in the Act—for the purposes of the Act<sup>24</sup>—as having occurred when there is irreversible cessation of either: (a) circulation of blood in the body of the person; or (b) all function of the brain of the person.

In circulatory death, *organs* rapidly degenerate due to lack of oxygen (ischaemia) rendering them unsuitable for transplantation. In contrast, *tissue* which is less susceptible to ischaemic damage may be suitable for transplantation for up to two hours after circulatory death.

In brain death, circulation is not affected and therefore both organs and tissue are able to be removed for transplantation. However, potential organ donors must be kept ventilated to preserve oxygen supply to the body.<sup>25</sup> Brain death can only be declared after a series of clinical criterion are met and must be certified by at least two experienced doctors who are not involved in the transplantation process.<sup>26</sup>

Therefore, the only viable source of cadaveric *organs* for donation is from people who die attached to a ventilator in an intensive care unit (ICU) of a hospital. This can make acceptance of 'death' difficult for family members. Brain death in these circumstances usually follows a sudden incident such as a motor vehicle accident, drowning or cerebrovascular accident (stroke).<sup>27</sup>

### 2.2.2 Authority to remove tissue or organs—the law and practice

The *Transplantation and Anatomy Act* (ss 22-23) requires that certain authority must be given in order for tissue (which includes organs) to be removed from a deceased person for transplantation.

---

<sup>22</sup> Ibid, pp 65-66.

<sup>23</sup> The *Transplantation and Anatomy Act* does not differentiate between deceased adults and children and therefore presumably the provisions discussed here apply to children. Although, there is a different definition of 'senior available next-of-kin' in the case of children. Different considerations also apply in showing that a child validly consented to donation: Qld Department of Health (P MacFarlane), *Queensland Health Law Handbook*, Brisbane, 1999, pp 159-160.

<sup>24</sup> *Transplantation and Anatomy Act 1979*, s 45(1). In Queensland, the statutory definition of death is only for the purposes of the Act. In other jurisdictions (except WA) the definition applies as part of the general law.

<sup>25</sup> Queensland Health submission dated 22 June 1999, p 5.

<sup>26</sup> Both medical practitioners must have clinically examined the person and one of them must be a specialist neurologist or neurosurgeon or have such other prescribed qualifications. Neither of the practitioners can be: the organ/tissue recipient of the donor; the designated officer who gives authority to remove the organ/tissue; or a practitioner who is proposing to remove organs/tissue from the body of a deceased person: *Transplantation and Anatomy Act 1979*, s 45(2). Only one submission to the committee's inquiry (Mrs S Savage submission dated 11 June 1999, p 2) expressed concern over whether 'brain death' was actually death.

<sup>27</sup> Queensland Health submission dated 22 June 1999, pp 5-6.

This authority differs depending on if, and how, the deceased expressed their wishes regarding donation while alive. Four scenarios are covered by the Act.<sup>28</sup>

Written consent. If a deceased person has expressed in *signed writing* during his or her lifetime a wish to be a donor and had not withdrawn that consent, the removal of their tissue for transplantation is authorised.<sup>29</sup>

However, this consent may be withdrawn orally at any time and Crown Law has advised that the mere indication of the preference to be a donor on a driver's licence does not comply with the requirements of s 22(6) of the Act, as it does not expressly provide that the removal of tissue is for any of the purposes referred to in s 22(1) of the Act.<sup>30</sup>

Oral consent. If a deceased person has *orally* expressed during his/her lifetime a wish to be a donor and had not withdrawn that consent, the 'designated officer' of the hospital in which the person has died can authorise by writing the removal of tissue for transplantation after making reasonable inquiries to ensure that the deceased had given oral consent and, if given, had not withdrawn that consent.<sup>31</sup>

Wishes not known. If a deceased person's wishes regarding donation are *not known*, the hospital's designated officer can still, in certain circumstances, authorise tissue removal. That is, where it appears to the officer after making reasonable inquiries that the deceased person had not expressed an objection to being a donor and the person's 'senior available next-of-kin' has consented to the donation.<sup>32</sup>

The 'senior available next of kin' is defined as being, in the case of a deceased adult, the first person reasonably available in the following hierarchical order of priority: a spouse, a son or daughter who has attained the age of 18; a parent; a brother or sister who has attained the age of 18. (A different order applies in relation to a deceased child.<sup>33</sup>) Several rules apply with respect to obtaining consent from a 'senior available next of kin'. For example, where there are two or more senior available next of kin in the same category, for example two brothers, then the objection of one prevails and the donation cannot proceed.<sup>34</sup>

Where a designated officer is unable to locate the deceased's next-of-kin, the officer can authorise the removal without the next-of-kin's consent if, after reasonable inquiries, they believe the deceased had not during their lifetime expressed an objection to donation.<sup>35</sup>

No consent. If a deceased person had during their lifetime stated either in writing or orally that they did *not* wish to be an organ donor (and they have not later changed their mind), then their tissue will not be removed.<sup>36</sup>

---

<sup>28</sup> Different considerations (and consents) apply where the coroner has jurisdiction to investigate a death and hold an inquest. *Transplantation and Anatomy Act 1979*, s 24.

<sup>29</sup> *Transplantation and Anatomy Act 1979*, s 22(6) and s 23(6).

<sup>30</sup> Crown Law advice to Queensland Health dated 21 July 1998. Even in the absence of the Crown Law advice, MacFarlane notes that the donor consent notation made on a driver's licence may not be considered as conclusive evidence of consent as this written consent may be withdrawn orally at any time: op cit, endnote 145, p 191.

<sup>31</sup> *Transplantation and Anatomy Act 1979*, s 22(1). A designated officer is the hospital's medical superintendent and persons appointed by the superintendent (being medical practitioners): *Transplantation and Anatomy Act 1979*, s 6(1).

<sup>32</sup> *Transplantation and Anatomy Act 1979*, s 22(2).

<sup>33</sup> *Transplantation and Anatomy Act 1979*, s 4.

<sup>34</sup> *Transplantation and Anatomy Act 1979*, s 4 and s 22(5).

<sup>35</sup> *Transplantation and Anatomy Act 1979*, s 22(3).

<sup>36</sup> If a person has stated an objection to donation in the past (either verbally or, for example, in a driver's licence), but it can be clearly shown that he or she since revoked that objection by way of oral statement, then that will amount to a revocation of the previous objection for the purposes of s 22 and s 22(4) of the Act: Crown Law advice to Queensland Health dated 21 July 1998.

### *The practice in hospitals*

Thus, if it is known that a person during their lifetime consented in writing to be a donor after death there is no *legal* requirement to obtain the consent of the next-of-kin. (Although, there may be a requirement to ask relatives whether the deceased had, at any time, revoked that consent given that a later oral revocation will override the earlier written consent.)

However, *in practice*, even though the deceased may have consented to organ donation, hospitals always consult the deceased's next-of-kin as a matter of policy.<sup>37</sup> If the next of kin agree to the donation they must sign a form which states that the deceased 'had not expressed an objection for the removal of tissue for transplantation'. **Where the deceased wished to be a donor and (any of the) the next-of-kin object, hospitals will not go ahead with the donation.** Hospitals will not go ahead: out of respect for the bereaved family; to avoid adverse publicity (which potentially could have a significant negative impact on community attitudes to organ donation and hence donation rates); and to avoid legal liability.<sup>38</sup>

It is the practice throughout Australia and in many other countries to consider the wishes of the deceased's family as an essential part of the organ donation process.<sup>39</sup> As one submission put it: 'No transplant donor surgeon in Australia is prepared to proceed with procurement unless they are secure in the knowledge that the donor family are supportive'.<sup>40</sup>

The need to respect the family's wishes is highlighted in the NHMRC booklet, *Donating organs after death: ethical issues*, which states:

*Organ and tissue donation is a decision which will affect those who are left behind after someone has died. Since the issue of organ donation often arises after a sudden and traumatic death, the feelings of the bereaved family are very important.*<sup>41</sup>

A number of submissions stressed that going against the family's wishes could have an adverse impact on organ donor rates. For example, Dr Wilkey of the Royal Brisbane Hospital stated:

*...the potential adverse publicity resulting from a confrontation between a hospital or transplant team and next-of-kin is very likely to affect adversely organ donor recruitment. The organ donation program can only be successful because of the altruism of members of the community. Adverse publicity is likely to be counterproductive.*<sup>42</sup>

As noted in chapter 1, the purpose of the bill appears to be to stop or circumvent this practice of consulting with the deceased's next-of-kin (at least in so far as it might allow the next-of-kin to

---

<sup>37</sup> This is in accordance with the National Health and Medical Research Council's, *Recommendations for the donation of cadaveric organs and tissues for transplantation*, AGPS, Canberra, June 1996, pp 5-8. These guidelines also set out what sort of information should be provided to the family in obtaining consent or an indication of non-objection to donate organs and tissue.

<sup>38</sup> This point was made in a number of submissions. For example: Ms T Cooper, Mr G Armstrong and Ms C Windle (donor coordinators, Princess Alexandra Hospital) submission dated 8 June 1999; Queensland Health submission dated 22 June 1999; Ms M Haire (Director Social Work Services, Prince Charles Hospital and District Health Service) submission dated 7 June 1999.

<sup>39</sup> Many submissions confirmed that this is the practice throughout Australia; for example: ACT Department of Health and Community Care submission dated 6 June 1999; Hon J Day, WA Minister for Health, submission dated 24 June 1999; Hon Dr M Wooldridge, Federal Minister for Health and Aged Care, submission dated 29 June 1999. This is also the practice in many European countries: *Meeting the organ shortage: Current status and strategies for improvement of organ donation*, European Consensus Document, p 19 (attached to Dr R Matesanz's submission dated 7 June 1999) and in the USA: see <<http://www.organdonor.gov>> downloaded on 22 July 1999.

<sup>40</sup> North Western Adelaide Health Service submission dated 18 June 1999.

<sup>41</sup> National Health and Medical Research Council, *Donating organs after death: ethical issues*, discussion paper no 1, 1997, p 3.

<sup>42</sup> Submission dated 18 May 1999.

prevent the donation proceeding) as a means to increase the number of organ donors in Queensland.

However, it is apparently very rare for families to overturn the deceased's wishes to be an organ donor where the deceased's intention is clearly known. Australians Donate cite a study in Victoria which indicated that 'where a patient's positive donor status is known at the time of declaration of 'brain death', in all cases the donor's family consented to donation. Where, however, donor status was not known, refusal rates were 39% of requests'.<sup>43</sup> In a 1998 state-wide survey conducted by Queensland Health, 94% of respondents indicated that they would provide consent for donation if an immediate family member died and had indicated willingness to donate their organs.<sup>44</sup>

A number of submissions to the committee's inquiry from those involved in organ donation also confirmed that it is very rare for families to overturn the deceased's wishes to be an organ donor where the deceased's intention is clearly known.<sup>45</sup>

### 2.2.3 Medical suitability

As a final precondition to cadaveric organ donation, the deceased's organs or tissue must be medically suitable. Suitability is dependent on factors such as the donor's age (age limits vary according to the organ or tissue) and medical and other conditions which render the deceased's organs unsuitable, such as malignant diseases, intravenous drug use, etc.

Once suitability is established, a donor's organs must be matched (in terms of blood group, tissue type etc) with a potential recipient. The organs must then be retrieved within the short time that organ viability can be maintained. Example storage times are: heart (4-6 hours), lungs (6-8 hours), liver (12-16 hours) and kidneys (24 hours).<sup>46</sup>

Therefore, time is of the essence in organ retrieval and a potential donor must be kept on a ventilator until such time as retrieval and consent can be organised. This time constraint means that decisions regarding organ donation are made at a time of great emotional stress and has implications for the organ donation process in Queensland given the state's decentralised nature.

Donor recipient waiting lists are kept by all states and territories.<sup>47</sup> Queensland patients will be given priority to receive an organ from a Queensland donor (although some patients can receive Australia-wide priority<sup>48</sup>). If a suitable recipient is not available in the donor's state or territory, the organ is offered to the other states on a rotational basis. Australia also exchanges organs with New Zealand.<sup>49</sup> In some cases, suitable organ recipients are never found.<sup>50</sup>

---

<sup>43</sup> Australians Donate submission dated 9 June 1999, p 4.

<sup>44</sup> Health Information Centre, Queensland Health, *Statewide Health Survey, Attitudes to Donation*, April-July 1998. In 1998, 23% of families volunteered consent for organ donation in Australia. Queensland had the highest number of donor families who volunteered consents—48% in 1998 followed by South Australia 23%, Victoria 20%, Western Australia 15%, NSW/ACT 12% and Tasmania and the Northern Territory 0%. Australia and New Zealand Organ Donation Registry (ANZOD), *ANZOD Registry 1999 Report*, Editors: Herbert K and Russ GR, Adelaide, 1999, p 21.

<sup>45</sup> See, for example: Dr C Naylor and Ms M Daly (John Tonge Centre for Forensic Sciences) submission dated 31 May 1999; Dr de Jersey (Townsville Health Service District) submission dated 26 May 1999; Victoria Institute of Forensic Medicine incorporating the Donor Tissue Bank of Victoria submission dated 10 June 1999; NSW Transplant Advisory Service submission dated 10 June 1999.

<sup>46</sup> Appendix A to Queensland Health's submission contains a list of maximum storage times and storage methods for various organs and types of tissue.

<sup>47</sup> For details of the waiting lists (on a per organ basis) see Easten, op cit, p 11.

<sup>48</sup> National Health and Medical Research Council, *Ethical issues raised by allocation of transplant resources*, Ethical issues in organ donation discussion paper no 3, AGPS, Canberra, 1997, p 11.

<sup>49</sup> For details of organs exchanged between Australian states and New Zealand see Easten, op cit, Appendix B.

<sup>50</sup> Following transplantation (particularly in the first three months), there is a considerable risk of organ rejection and infection. St Luke's Nursing Service submitted to the committee that there needs to be a focus on those who



It should also be noted that organ/tissue retrieval can only be performed by qualified staff who work within a Therapeutic Goods Authority approved centre.<sup>51</sup>

### 2.3 AUSTRALIA'S AND QUEENSLAND'S DONOR RATE

Only very few people—around 1% of all people who die—are capable of becoming organ donors. As explained above, this is because organ donation can only take place where a person has died as a result of an incident such as a serious accident or a brain haemorrhage and they are in hospital on a ventilator.<sup>52</sup>

Australia's organ donation rate over the last four years has averaged at 10-11 donors per million of the population (dpmp).<sup>53</sup> This can be compared with Spain which has the highest organ donation rate in the western world at currently 32 dpmp.<sup>54</sup>

In 1998, Queensland had 12 dpmp (40 donors) which was the third highest in Australia after South Australia whose dpmp was 24 (35 donors) and the Northern Territory's whose dpmp was 16 (3 donors).<sup>55</sup>

As noted in chapter 1, the Member for Thuringowa in his second reading speech stated that Australia has one of the lowest organ donation rates in the western world. However, a number of submitters stressed that interstate and international comparisons of donor rates are not always meaningful because they do not allow for differences in community education, religion, factors affecting the death rate, etc. In Queensland, a number of factors have contributed to fewer deaths particularly in this decade. These factors include: the reduction in the road toll, the decrease in drowning rates via the introduction of compulsory pool fences, the introduction of mandatory bicycle helmets, and advancements in the treatment of hypertension and subsequent reduction in strokes.<sup>56</sup>

For this reason, some propose that the actual number of deaths (and therefore the ability of people to be donors) might provide a more valid basis upon which to compare donation rates.<sup>57</sup>

### 2.4 WHY PEOPLE DO/DO NOT DONATE

A 1995 survey showed that up to 90% of Australians support the principle of organ donation.<sup>58</sup>

A 1998 state-wide survey by Queensland Health also provided information on community attitudes to donation. 72% of respondents said that, in the event of their death, they would be

---

have had unsuccessful transplants and a forum for bereaved families to air their negative experiences: submission dated 10 June 1999.

<sup>51</sup> Queensland Health submission dated 22 June 1999, p 5.

<sup>52</sup> Queensland Health advises that in the 1995/96 financial year, 11 527 people died in hospital in Queensland and approximately 0.5% of these became organ donors. A benchmark of 1% has been identified as the ideal target rate for organ donation: Queensland Health submission dated 22 June 1999, p 5.

<sup>53</sup> ANZOD, 1999 report, op cit, p 4.

<sup>54</sup> Spain's organ donor rate is further discussed in chapter 3.

<sup>55</sup> In examining 1997 figures for donors per thousand deaths Queensland was also third highest (1.71) to the Northern Territory (4.5) and South Australia (2.16): ANZOD, 1999 report, op cit, pp 4-5.

<sup>56</sup> Queensland Health points out that this is possibly why Queensland's organ and tissue donor rate began to significantly decrease during the early 1990s: submission dated 22 June 1999, pp 4-5. St Luke's Nursing Service also pointed out that many people choose to die in their homes surrounded by loved rather than in an ICU (which would also render them incapable of becoming an organ donor).

<sup>57</sup> Queensland Health submission dated 22 June 1999, pp 4-5; ANZOD, 1999 report, op cit, p 5.

<sup>58</sup> Survey conducted by Frank Small and Associates: results are from the ACCORD website <<http://www.span.com.au/span/accord/attitudes.html>> downloaded on 14 July 1999.

willing to donate one or more of their organs or tissue for transplant. 18% said that they would not be willing and 10% did not know.<sup>59</sup>

There are a number of reasons why people might not wish to consent to being an organ donor (or might not consent to a deceased next-of-kin being a donor). These reasons include:

- a lack of understanding of the process;
- a fear that the process might upset the family;
- a concern that they might be too old for organ donation;
- a concern that doctors may not try as hard to save a potential donor's life;
- a concern that they may not be really dead; and
- discomfort with the idea of their body being disfigured.<sup>60</sup>

Some people also choose not to donate on religious or spiritual grounds. Although, the majority of the world's religions support organ donation and transplantation.<sup>61</sup>

## 2.5 RECORDING DONOR INTENTION

There are a number of ways in which a person can record their intention to become an organ donor.<sup>62</sup> Some of the more common ways are discussed below. (However, as discussed further in chapter 5, it is not only the recording of a decision that is important; what is also critical is that the potential donor discusses the issue of donation with their family.)

### 2.5.1 The use of drivers' licences

All Australian states, except Victoria, give the holder of a driver's licence the option of recording their willingness to be an organ donor on their licence. (In Victoria, organ donation programs are administered by the Transplant Promotion Council and the Organ Donor Registry. The Council runs publicity campaigns designed to encourage people to donate organs. The Registry maintains a list of people interested in giving their organs for transplant.<sup>63</sup>)

Out of all Australian jurisdictions, Queensland enjoys the highest rate of positive donor status indicated on drivers' licences.<sup>64</sup> Approximately 54% of Queenslanders who hold a driver's licence have elected to record their willingness to be an organ donor on their licence. Of the remaining licence holders, approximately 35% have refused to consent to organ donation and 11% are undecided or have not provided any indication. Slightly more female drivers consent to organ donation than male drivers.<sup>65</sup>

In 1998, 28% of actual organ donors in Australia had indicated their consent to organ donation on their driver's licence. In 1997, the figure was 24%. In 1998, 14 of the 40 Queensland organ donors

---

<sup>59</sup> Health Information Centre, Queensland Health, *Statewide Health Survey, Attitudes to Donation*, April-July 1998. Telephone survey to one adult per household. 5,594 interviews. Response rate of 72%.

<sup>60</sup> Ibid. The Queensland Health survey contains a further breakdown of the reasons given by those 28% who were unwilling to consent or unsure about consenting to organ donation.

<sup>61</sup> ACCORD website <<http://www.span.com.au/span/accord/factsheet.html>> downloaded on 14 July 1999; Easten, op cit, p 17 and Appendix J (Religious views on organ donation).

<sup>62</sup> Separate and specific permission is required to use a body for medical or scientific purposes: *Transplantation and Anatomy Act*, s 22(1).

<sup>63</sup> Hon G Craige, Victorian Minister for Roads and Ports, submission dated 15 June 1999.

<sup>64</sup> *Australians Donate, Organ donor status on driver's licences survey*, summary of findings, August 1998 (attached to *Australians Donate* submission dated 9 June 1999). This survey shows that 56.13% of Queenslanders have recorded a consent to organ donation on their licence.

<sup>65</sup> Easten, op cit, p 12. These figures are based on information from Queensland Transport as at Nov 1998.

(35%) had indicated this consent on their driver's licence. This is compared to 16 of the 37 organ donors in 1997 (43%).<sup>66</sup>

**However, the value of the donor consent notation on a Queensland driver's licence is largely negated because that information is not available to those involved in the organ donation process.** Section 14A of the *Traffic Act 1949* (Qld) prevents the release of driver's licence information to 'another person' without the driver's written agreement. Therefore, it operates to deny donor coordinators access to the licence database in order to establish whether a person has consented to being an organ donor on this licence.

Submissions also made it clear that the potential value of collecting donor consents on drivers' licences is additionally undermined by the fact that:

- the circumstances of accidental death seldom mean that a potential donor is carrying their driver's licence (Queensland Health advised that the driver's licence or an organ donor card is only sighted in about 9% of organ donation situations<sup>67</sup>);
- since presently there is no central register of potential donors (which is nationally accessible), there is a risk that a person's intentions with respect to organ/tissue donation may either be overlooked or not discovered in time to permit donation to occur, especially when the person dies interstate;
- there is the danger that the method by which licence holders indicate their intentions cannot be said to be truly 'informed consent'; and
- there is no mechanism whereby holders are encouraged to discuss their intentions with their next-of-kin.<sup>68</sup>

### 2.5.2 Other ways to record donor intention

There are a number of other ways in which people can record their intention to become a donor. These include:

- a donor card<sup>69</sup> (the Australian Kidney Foundation provides free donor cards);
- a donor clause in a person's will;<sup>70</sup> and
- completion of a donation form distributed by transplant coordinators on request.<sup>71</sup>

In 1998, only seven Australian organ donors (3.5%) had signed a donor card. No organ donors in Queensland has signed a donor card.<sup>72</sup>

A further way to record donor intention is explored in chapter 5.

---

<sup>66</sup> ANZOD, 1999 report, op cit, p 20, figure 36. In 1997, the figures were 24.2% nationally and 43.2% for Queensland.

<sup>67</sup> Submission dated 22 June 1999, p 12.

<sup>68</sup> Australians Donate submission dated 9 June 1999.

<sup>69</sup> The suggestion has also been made that credit cards could also act as an organ donation card, at least until smart cards incorporating medical information become widely available: *British Medical Journal* (1998) website <<http://www.bmj.com/cgi/content/full/317/7156/478/9>> downloaded on 21 July 1999.

<sup>70</sup> The Public Trustee advises the committee that the issue of organ donation arises during the normal course of taking a client's instructions for the preparation of their will: letter from the Public Trustee to the committee dated 8 June 1999. The committee also understands that the Adult Guardian supports organ donation clauses in wills: meeting of the committee with Queensland Health officers on 27 May 1999.

<sup>71</sup> Queensland Health advises that the transplant coordinators at the Princess Alexandra Hospital have devised a form to enable people to indicate their wishes, including the specifics of which tissue/organs they wish to donate. Submission dated 22 June 1999, p 11.

<sup>72</sup> ANZOD, 1999 report, op cit, p 20, figure 38.

### 3. WAYS TO INCREASE ORGAN DONATION

In his second reading speech, the Member for Thuringowa urged Queensland to introduce a model designed to increase the number of organ donors. In this regard the Member referred to the organ donation models or systems used in Spain and South Australia, but noted that:

*Whether Queensland adopts the 'Spanish model', or something similar to the South Australian system, or we create our own system is irrelevant. What we need to do is ensure that as few as possible potential donors are missed.*<sup>73</sup>

There are two broad options which jurisdictions might adopt to seek to increase their organ donor rates. These are:

- a 'presumed consent' or 'opting out' system (used in many European countries) which relies on a presumption that a deceased person's organs are available for donation unless the person had expressed a contrary wish and had that wish appropriately recorded; and
- an 'opting in' system which allows an individual to choose to donate their organs upon death and make this decision known before their death. The individual's consent will not be presumed.

All Australian states and territories have policies based on the 'opt in' system.<sup>74</sup> However, in the circumstances outlined in section 2.2.2, the next-of-kin can make a decision regarding organ donation where the deceased had not done so during their lifetime.

#### 3.1 THE SPANISH MODEL

The so-called 'Spanish model' of organ donation, devised by Dr Rafael Matesanz, has attracted international interest in the field of organ donation and transplantation. Since implementing this strategy in 1989 (via the Organizacion Nacional de Transplantes or ONT), Spain's donor rate has risen from 14 dpmp to 32 dpmp in 1999 which is by far the highest in the world.<sup>75</sup>

The model recognises that donation and transplantation is a complex process involving different steps that must be integrated. Central to the model are transplant coordinators who are part-time medical doctors located inside hospitals with intensive care units. The main aim of the transplant coordinators is to procure organs which they do by directly requesting donation of organs and tissue. The coordinators are assisted by full-time dedicated nurses and work closely with other agencies involved in organ donation. Responsibility and accountability is decentralised to provincial and local levels, with national coordination and a regional coordinating network.<sup>76</sup>

Queensland Health advises that whilst some principles of the Spanish model have been incorporated in the program Queenslanders Donate (discussed later in this chapter), a number of factors differentiate Spain from Queensland.

---

<sup>73</sup> Mr K Turner MLA, Transplantation and Anatomy Amendment Bill 1998, *Queensland Parliamentary Debates*, Second Reading Speech, 10 November 1998, p 2819.

<sup>74</sup> An opting out system has been considered but rejected in Australia. See ALRC, *op cit*, pp 67-68 and Easten, *op cit*, p 19.

<sup>75</sup> Dr Matesanz submission dated 7 June 1999. Although, Queensland Health points out that there are some differences in definitions used in Spain and Queensland which might have a slight impact on these figures: submission dated 22 June 1999, pp 8-9.

<sup>76</sup> From the outset, the model has stressed that one person or group is to be responsible for the organ/tissue procurement and transplantation (or storage) for each potential donor in each hospital: R Matesanz and B Miranda, 'The Spanish experience in organ donation' in J Chapman, M Deierhoi and C Wight (eds), *Organ and tissue donation for transplantation*, Arnold, Sydney, 1997, pp 361-372 at pp 362-363.

*The major differences for Queensland are that Spain has the highest doctor to population ratio in developed countries and can therefore afford to employ medical coordinators. Also the country has a more religiously homogenous population which is accepting of transplantation. Australia is a more multi-cultural nation with a range of ethnic backgrounds and religious beliefs. The Brennan Report (1997) acknowledges the need for a special approach to ethnic and Indigenous populations in Australia.*

*The lessons to be learned from the Spanish model are decentralisation, local accountability, measures of performance, and professionalism in managing donor families before, during and after the consent and donation process (Brennan 1997). The procurement rate mainly results from efforts to overcome obstacles such as untrained staff, unidentified donors and reluctance to approach grieving families. The key issue identified is not just a lack of donors but the failure to turn potential donors into actual donors (Matesanz & Miranda, 1997).<sup>77</sup>*

The Health Committee of the Transplant Committee of the Council of Europe has recently approved the European Consensus Document ‘*Meeting the organ shortage: current status and strategies for improvement of organ donation*’ which is largely based on the Spanish Model.<sup>78</sup>

### **3.2 THE US MODEL**

In December 1997, the US Department of Health and Human Services launched its National Organ and Tissue Donation Initiative. In the first full year of the initiative (1998), organ donation increased 5.6%. The elements of this initiative which have been seen as contributing to its success include:

- a 1998 regulation which requires hospitals to notify organ procurement organisations (OPOs<sup>79</sup>) of all deaths and imminent deaths so potential donors are identified and families are asked about donation (although only designated, trained individuals discuss donation with the next-of-kin); and
- strategies (in conjunction with various organisations in the private and volunteer sectors) to increase community awareness of the need for organ and tissue donation. These strategies focus on informing individuals that, once they make the decision in favour of organ donation, they need to share their decision with their families since families are ultimately asked to give consent before donation can occur.

The department has also conducted a national conference aimed at identifying the most effective evaluation strategies for activities to increase donation and transplantation, and funded research on why families consent or refuse to consent to the donation of organs of a family member.<sup>80</sup>

The US had previously trialed, unsuccessfully, ‘required request’ legislation whereby hospitals were required to ask the next-of-kin of all potential cadaveric donors for consent to donate.<sup>81</sup>

---

<sup>77</sup> Queensland Health submission dated 22 June 1999, p 7.

<sup>78</sup> Attached to the submission of Dr Matesanz dated 7 June 1999.

<sup>79</sup> OPOs coordinate activities relating to organ procurement in a designated area. They evaluate potential donors, discuss donation with family members and arrange for the surgical removal of donated organs. OPOs are also responsible for preserving organs and arranging for their distribution according to national organ sharing policies. See <<http://www.organdonor.gov/opo.htm>> downloaded on 22 July 1999.

<sup>80</sup> See the HHS fact sheet <<http://www.hhs.gov/news/press/990416.html>> downloaded on 21 July 1999. The HHS department states that two recent surveys on donation both confirm that nearly all Americans would consent to donation if they knew their loved one had requested it. However, only half or fewer would consent if they were unaware of their wishes.

<sup>81</sup> Easten, op cit, p 21.

### 3.3 THE SOUTH AUSTRALIAN MODEL

The South Australian Organ Donation Agency (SAODA) was established in June 1996 to: coordinate organ donation; promote awareness of organ donation within the community; recognise and meet the needs of recipients; preserve fully the dignity of donors and recognise and meet the needs of donor families.<sup>82</sup> SAODA is based on the successful Spanish model of organ donation.

SAODA is funded by the South Australian Department of Human Services and provides central administrative support to three (non-medical) donor coordinators who work with medical donor coordinators within the state's major hospitals. SAODA has an annual budget of approximately \$500,000 which incorporates salaries for agency staff (including donor coordinators), administration and premises, and funding provided to intensive care units for medical donor coordinator services.

All medical donor coordinators are senior intensive care consultants who have additional duties, including to: identify potential organ donors within the hospitals; discuss with relatives in conjunction with the transplant coordinators the option of organ donation; provide medical assistance to the donor coordinators in the initial stage of the donation process; clinically manage the donor; identify issues that assist or limit donor procurement in and outside the hospital; and provide education and policy input from the intensive care perspective regarding organ donation within the hospital. SAODA reimburses the intensive care unit for these services.<sup>83</sup>

Medical donor coordinators generally refer a potential donor to a donor coordinator. Both then approach the family to discuss organ donation. The donor coordinator makes all of the donor arrangements (including tissue typing, virology testing, liaising with transplant units, operating theatres, etc) and provides the essential immediate support and follow-up care for donors' relatives (considered essential to a successful donation program). The donor coordinators also provide education to hospital staff and the community.

In its first three years of operation, SAODA successfully lifted South Australia's donor rate from 15 dpmp in 1995 to 23 dpmp in 1998. This is the highest organ donation rate in Australia and more than double the national donation rate for 1998 of 10.5 dpmp.<sup>84</sup> The organ donation rate has increased despite a decrease in road trauma (from 39% of donor deaths in 1996 to 14% in 1997).<sup>85</sup> In 1998, 24 out of 62 organ donation referrals did not eventuate. 11 of these refusals were family refusals.<sup>86</sup> To assist in ascertaining whether donors are missed and to estimate the realistic donor potential, the agency has conducted 'death audits' in 5 public hospitals.<sup>87</sup>

A number of factors are said to contribute to South Australia's relatively high rate of donation including:

- improved communication leading to a more proactive donation system within hospitals;

---

<sup>82</sup> The information in this section is largely drawn from G Dahlenburg, K Herbertt, *Annual report of the activities of the South Australian Organ Donation Agency 1998*, Adelaide, 1998, pp 4-6.

<sup>83</sup> Queensland Health advises that this is reported to be in the range of \$20 000-\$40 000 per annum depending on the size of the hospital and that 'such a system would have significant resource implications for Queensland Health with 25 donor hospitals, both in terms of workforce planning and recurrent costs'. Submission dated 22 June 1999, p 8.

<sup>84</sup> Dahlenburg and Herbertt, *Annual report of the activities of the South Australian Organ Donation Agency 1998*, op cit, pp 6 and 11.

<sup>85</sup> G Dahlenburg and K Herbertt, 'State Organ donation activity update (South Australia)', abstract of paper presented at the inaugural national forum on organ and tissue donation, April 1999, Canberra.

<sup>86</sup> Dahlenburg and Herbertt, *Annual report of the activities of the South Australian Organ Donation Agency 1998*, op cit, p 6.

<sup>87</sup> Ibid, p 14.

- more proactive and aware intensivists who encourage and support families of brain dead relatives in ICUs to consider donation;
- the size and centralisation of the state (particularly as compared to Queensland<sup>88</sup>); and
- the fact that South Australia's four main tertiary hospitals are in Adelaide, in relatively close proximity to most donors and secondary hospitals.<sup>89</sup>

### 3.4 AUSTRALIANS DONATE

Australians Donate is a new national organisation (based in Adelaide) which aims to maximise organ and tissue donation for transplantation and to enhance community confidence in the donation and transplantation systems. Australians Donate was established in 1997 to replace the previous organisation, Australian Coordinated Committee on Organ Registries and Donation (ACCORD), and is jointly funded by the Commonwealth and the states and territories.<sup>90</sup>

Australians Donate has the key responsibilities of: lifting donor rates nationally; improving the coordination and networking of existing donor registries and databases nationally; and implementing public and professional education programs to raise awareness and understanding of organ/tissue donation issues. To this end, Australians Donate has endorsed a national direction which aims to:

- provide public, professional and school education programs;
- sympathetically manage donor families' issues and problems;
- build donor databases and providing improved data access for coordinators;
- improve data flow between those participating in the network;
- provide incentives at a hospital level to identify and manage potential donors; and
- actively encourage positive media coverage of organ and tissue donation.<sup>91</sup>

The National Council of Australians Donate<sup>92</sup> met for the first time on 12 October 1998 and Australians Donate organised the first national organ donation conference held in Canberra in April 1999.

Australians Donate is currently pursuing the proposal of a national computer database of registered donors which could be accessed from any hospital in the country. (This is discussed further in chapter 5.)

### 3.5 QUEENSLANDERS DONATE

Queensland Health advised that it is currently committed to a range of strategies aimed at increasing the rates of organ and tissue donation in Queensland. In particular, in the 1998/99 budget new initiative funding of \$323 000 was provided to establish 'Queenslanders Donate', a

---

<sup>88</sup> Queensland Health states that in 30 minutes it is possible to fly to South Australia's borders. In contrast, 30 minutes flying in Queensland would only reach Bundaberg. Submission dated 22 June 1999, p 6.

<sup>89</sup> Dahlenburg and Herbertt, *Annual report of the activities of the South Australian Organ Donation Agency 1998*, op cit, p 6. Queensland Health submission dated 22 June 1999, p 6.

<sup>90</sup> This followed a recommendation from the Australia Health Ministers' Advisory Council, *Review of Australian Coordinating Committee on Organ Registries and Donation*, conducted by Dr P J Brennan & Co, September 1996 ('the Brennan report').

<sup>91</sup> Ibid.

<sup>92</sup> The National Council comprises approximately 20 councillors who are broadly representative of all the stakeholders. No jurisdiction dominates the council and no more than five councillors are to be resident from the host state. Australians Donate also has a management committee which is responsible for overseeing the financial and operational management of the organisation. Queensland is represented on both bodies.

program which Queensland Health describes as ‘a comprehensive and coordinated approach to organ donation within the State’s hospitals’.<sup>93</sup>

Queenslanders Donate has been developed following wide consultation with experts in the field of organ donation and transplantation.<sup>94</sup> The program combines the strengths of several other organ donation models but takes into account the impact that the decentralised nature of Queensland has on time-frames for successful negotiation and retrieval of donated organs. As noted in chapter 2, time is of the essence in organ retrieval and a potential donor must be kept on a ventilator until such time as retrieval and consent can be organised. (Queensland’s major tertiary hospitals are all located in Queensland’s south-eastern corner and not within easy reach of the majority of donors and secondary hospitals. The major provincial hospitals are also a considerable distance from Brisbane.)

Key elements which Queenslanders Donate plans to implement are: effective liaison between hospitals (particularly ICUs and intensivists) and donor coordinators<sup>95</sup>; identification of potential donors (particularly via ‘death audits’ which seek to detect the gap between potential donors and actual donors in each hospital/area<sup>96</sup>); and facilitation of an organ donor awareness program. Queenslanders Donate seeks to, for the first time, establish a cohesive network of staff involved in organ and tissue donation, retrieval and transplantation. This, Queensland Health advises, will be achieved by:

- working with the newly formed Transplant Clinical Advisory Committee whose prime role will be to oversee and provide policy direction;
- working closely with Australians Donate;
- gaining access to the Queensland Transport data base on potential donors and managing a Queensland Health Donor Registry (discussed further in chapter 5); and
- providing education material on organ and tissue donation to all participating hospitals, District Health Services and Queensland Transport for distribution with driver’s licence renewals (discussed further in chapter 5).

The organisational structure of Queenslanders Donate includes a manager (to coordinate the network), a social worker (to support donor families), and 7 intensive care ‘link nurses’ throughout Queensland. These link nurses, who are considered vital to the program, will be a link between the hospital and the donor coordinator centre. They will work one day per week in

---

<sup>93</sup> Queensland Health submission dated 22 June 1999, p 13.

<sup>94</sup> In May 1997, the Transplant Services Advisory Committee (TSAC) was formed to, among other matters, develop a framework to enhance the organ/tissue donation rate in Queensland. In February 1998, TSAC endorsed a discussion paper *Queenslanders Donate: A new way forward* which drew together the committee members’ opinions as to how transplant services might be more efficiently and effectively organised. Queenslanders Donate emerged from submissions in response to that paper: Queensland Health submission dated 22 June 1999, pp 13-14.

<sup>95</sup> The role of donor coordinators is to coordinate the retrieval of organs and tissue for transplantation. Their responsibilities include ensuring that the legal and medical criteria associated with organ and tissue donation are met. See Ms T Cooper, Mr G Armstrong and Ms C Windle (donors coordinators, Princess Alexandra Hospital) submission dated 8 June 1999.

<sup>96</sup> In order to increase organ donation, other states are also conducting ‘death audits’ of their hospitals (J Robotham, ‘Push to increase organ donor levels’, *The Age*, 12 April 1999, p 6) and developing organ donor indices to compare hospital donor rates (I Pearson and J Chapman, ‘Improving organ donor rates’, *Medical Journal of Australia*, vol 170, 17 May 1999, pp 463-464 and A Holt, G Hodgeman, A Vedig and P Heard, ‘Organ donor index: a benchmark for comparing hospital organ donor rates’, *Medical Journal of Australia*, vol 170, 17 May 1999, pp 479-481). Identification of potential organ donors was a topic of discussion at the April 1999 inaugural national forum on organ and tissue donation.



metropolitan and provincial hospitals to educate and increase awareness of intensive care unit staff and to conduct audits of deceased persons to determine the causes for missed potential donors.<sup>97</sup>

In particular, Queenslanders Donate encourages more active involvement of intensivists in the organ donation process by analysis of the results of death audits, education about organ donation and support from link nurses.

Australians Donate observes that Queenslanders Donate adopts the key elements of:

- being a centralised, staffed and separately and adequately funded agency;
- representing all major players in the state's donation infrastructure; and
- clearly separating the donation agency from transplant units.<sup>98</sup>

Queensland Health intends to evaluate the program within 12 months.

---

<sup>97</sup> Queensland Health submission dated 22 June 1999, p 15.

<sup>98</sup> Submission dated 9 June 1999, p 6. Australians Donate also stresses that it is important that there is a clear separation between the ICU and the transplant teams so that the latter has no role in the treatment of any ICU patient and nor are they in a position to apply pressure to salvage organs needed for transplantation.

## 4. SHOULD THE BILL BE SUPPORTED?

As part of its consideration of the bill, the committee has essentially examined two issues: (a) Would the bill achieve its objective of increasing organ donor rates? (b) Are there good policy reasons why the Parliament should/should not adopt the bill? The committee has consulted widely for assistance in answering these two issues.

In this chapter, the committee reaches a conclusion on these matters and whether the bill should be supported by the Parliament. As a result of the committee's deliberations, the committee additionally comments on the adequacy of the current law in Queensland regarding organ and tissue donation after death.

### 4.1 EVALUATION OF THE BILL

Clearly, organ donation and transplantation raises not only legal and medical considerations, but also important ethical, social, and cultural issues.

As the background discussion in this report highlights, at the core of organ donation are two (competing) principles. Organs and tissue from deceased persons can, in suitable cases, be used to save lives and enhance the well-being of others. However, there is also a need to respect individual autonomy and ensure some form of consent on the part of the deceased donor regarding the removal and use of their organs and tissue.<sup>99</sup> These interests might therefore be broadly put as the recipient's and the wider community interest on the one hand, and the donor's (and their family's) interest on the other.

The ALRC noted in its 1977 report, *Human Tissue Transplants*:

*The principal issue for lawmaking on cadaver tissue donation is whether the community has a sufficient interest, or 'right', in dead bodies to support a claim to human tissues which can be used for the public benefit, and if so, in what circumstances, and with what restrictions. An aspect of the same issue is the determination of the extent, if any, to which the individual, or his relatives after his death, should, in relation to the therapeutic use of human tissues, have power to control what will happen to his dead body.*<sup>100</sup>

These broad competing interests must be considered in the context of Australia's multi-cultural society which brings with it diverse religious, ethical and moral beliefs. These factors influence the individual and the community perception and acceptance of organ donation.

In addition, regard must be given to the ethical considerations of the medical profession involved in organ donation and transplantation.

The committee is concerned that its response to the bill is informed by, and sensitive to, the many interests at stake.

#### 4.1.1 Issues raised in public consultation

Of the 53 submissions received by the committee, the majority of those which expressed a definitive view on the bill did not support it. The general theme of these submissions was that, whilst the intention of the bill (to increase the organ donor rate) is good, its objective can be achieved by other, more effective means.

---

<sup>99</sup> MacFarlane, op cit, p 157.

<sup>100</sup> ALRC, op cit, p 64. The current law regarding cadaveric organ donation (described in chapter 2) represents where the ALRC saw the appropriate balance between the competing principles.

As Australians Donate noted:

*We find ourselves in agreement with the Bill's principal objective - and that is to bring forward the decision to register as an intending donor, rather than leave that weighty decision for the highly stressful and emotional environment of an Intensive Care Unit (ICU), when the donor is approaching "brain death". We are however at odds with the Bill on the subject of how to achieve that objective.*<sup>101</sup>

Submissions also stressed that the reasons for organ shortage are far more complex than solely the issue of consulting donors' families.

### Submissions not supportive of the bill

A clear message made in submissions not supportive of the bill was that, irrespective of the legal situation, the deceased's family should (and probably must) be involved in the decision to remove organs for transplantation.

Mrs P den Ronden stated that 'legalising' a driver's consent would be 'a callous affront to the loved ones who are left to grieve'.<sup>102</sup> Dr C Naylor and Ms M Day from the John Tonge Centre for Forensic Sciences also stated:

*Given that the types of deaths that result in organ/tissue donation are usually tragic and unexpected, it is imperative that tissue and organ donation programs somehow accommodate the sensitivities of the deceased's family and avoid causing unnecessary additional distress. Many families who have consented to organ/tissue donation consider this decision provided them with something positive to come out of an otherwise tragic situation. This is because they are consulted, and provided with the opportunity to consider donation, rather than it proceeding against their wishes. The danger of the proposed Bill is that needs of the family may be disregarded once consultation is no longer a legal necessity. This may then lead to complaints and adverse publicity, which may reduce the availability of organs and tissues.*<sup>103</sup>

Submissions also made it very clear that from an ethical and pragmatic perspective the physician in charge will do nothing against the family's wishes. The Victorian Institute of Forensic Medicine (incorporating the Donor Tissue Bank of Victoria) submitted:

*In our experience at the DTBV, one of the key factors in successfully obtaining human tissue for donation is ensuring that family members of the deceased are treated with respect and that consultation about tissue donation is conducted with sensitivity and compassion. We believe this approach to have a sound ethical base and to be consistent with standards that have been evolving over a number of years in the human tissue donation field, and which are now generally applied across Australia and in other jurisdictions where ethically based donation programs are administered (whether or not there is legislation requiring such consultation).*<sup>104</sup>

As noted in chapter 2, consultation with a potential donor's family is considered an integral part of the organ donation process in many countries. It is clearly integral to the highly successful Spanish organ donation model. As Dr Matesanz advised the committee:

*In Spain we always ask for family permission despite the presence of a donor card or some other document, and I think it is better to lose one donor than a conflict with a family with personal, mediatic and legal complications.*<sup>105</sup>

---

<sup>101</sup> Submission dated 9 June 1999, p 3.

<sup>102</sup> Submission dated May 1999, p 2.

<sup>103</sup> Submission dated 31 May 1999, p 2.

<sup>104</sup> Submission dated 10 June 1999, p 2.

<sup>105</sup> Dr Matesanz submission dated 7 June 1999.

Australians Donate stressed the potential damage that could flow from negative media coverage regarding organ and tissue donation brought about by a disaffected donor family:

*The Member correctly identifies negative media coverage of organ/tissue donation as being a major determinant of public attitude toward donation. Since in 1998 there was a total of only 40 solid organ donors in Queensland, the creation of any form of adverse public comment by a disaffected donor family may well damage public confidence in the donation process, to a degree out of all proportion to the good intentions of the Bill.*

*Donor families can be a powerful positive force in our quest to lift donation rates. We would prefer that the wishes of donor families be respected, even if that means that they retain the right of veto over a donation. It is our responsibility to aim to refine donation processes so that donor families can derive comfort rather than anguish from donation. This has been one of the major success of SAODA, with the formation of the donor family support group, GIFT.<sup>106</sup>*

Various other reasons were also given for not supporting the bill. These included the following.

- In essence, the bill assumes that the shortage of organs and tissue for donation is principally related to the need to consult with the deceased's next-of-kin and that this could be overcome by giving the donor consent notation on a driver's licence legal force. This assumption is false because:
  - the next-of-kin of some potential donors are simply not approached either because the patient is not recognised as a potential donor, or because medical/nursing staff are reluctant to make the approach;
  - where the deceased's wishes regarding organ donation have been known via their driver's licence or during prior family discussion during the deceased's lifetime, the next-of-kin are unlikely to go against the wishes of the deceased; and
  - next-of-kin approached in a sensitive manner (especially by trained and sensitive professionals) are likely to grant consent.
- A driver's licence is not always a reliable indicator of a person's wishes (for example, the driver might have changed their mind since they renewed their licence or an administrative error might mean that a donor notation is recorded incorrectly<sup>107</sup>, etc).
- People who make the decision to have a donor intention recorded in their licence often make that decision at the transport customer centre when applying for/renewing their licence. A question arises as to how real/informed that consent is, at least based on current procedures. As Queensland Health stated, 'This is not the ideal situation to be making important decisions about donation'.<sup>108</sup> Dr Matesanz also noted that when people get their licence they are 'unlikely to be correctly informed about what organ donation means'.<sup>109</sup>
- In any case, the tragic events leading to a person's admission to an ICU often means that they will not be carrying their driver's licence (or an organ donor card).
- A donor consent notation on a driver's licence, even if 'binding' consent, would still not eliminate the need for the hospital to consult with the family to: (a) check whether the deceased had withdrawn their consent to organ donation; and (b) obtain information on the

---

<sup>106</sup> Submission dated 9 June 1999, p 3.

<sup>107</sup> Ms T Cooper, Mr G Armstrong and Ms C Windle (donor coordinators, Princess Alexandra Hospital) stated that in NSW computer data entry on 16% of licences was incorrect and that there have been several cases in Queensland brought to their attention where an incorrect entry was recorded on a licence: submission dated 8 June 1999, p 3.

<sup>108</sup> Submission dated 22 June 1999, p 9.

<sup>109</sup> Submission dated 7 June 1999.

social/medical history of the deceased (for example, to establish lifestyle risk factors in the deceased such as intravenous drug use which are used to exclude some potential donors).

- The bill, by focusing on drivers, misses a group of potential donors who are either not drivers or who are too young to have a licence.
- Organ donation is a sensitive issue and those who do not wish to be involved should be under no pressure to donate organs.
- If the bill was passed there would have to be careful consideration given to managing the transition from the current system where a licence marked organ donor is simply advisory to the new system where such a notation is legally binding.

Instead, submitters opposed to the bill suggested a number of alternative strategies to increase and improve the rate of organ/tissue donation. These included:

- establishing a donor database accessible by Queensland Health/donor coordinators which would allow donor coordinators to have knowledge of a person's consent before they approach the next-of-kin;
- ensuring potential donors are making 'full and informed' consent to organ donation which, in the case of drivers, means that they are provided with sufficient, appropriate information before being asked whether they wish a donor consent notation to appear on their licence. This information should specify which organs and tissue are included in that consent and give the person the ability to exclude particular organs and tissue;
- providing hospital staff with training to identify suitable donors and improve their skills in approaching families regarding organ donation;
- establishing/maintaining on-going public awareness/education programs about organ donation which also encourage people who have made the decision to be a donor to inform their next-of-kin of that decision (regardless of whether they record that decision by way of their driver's licence) as evidence suggests that where a potential donor communicates their decision to their family, their family are more likely to uphold their wishes at the time of their death; and
- implementing/maintaining support programs for donor families which acknowledge the gift they have given.

The committee discusses some of these suggested strategies further in chapter 5.

#### Submissions supportive of the bill

The minority of submitters who supported the bill did so mainly for three reasons.

Firstly, it would reduce stress on the family members at a difficult time (that is, their affirmation of the deceased's wishes would not be necessary). Friends of the Donor Tissue Bank of Victoria submitted:

*The majority of our members have been through the heart breaking decision to donate tissue for a recently deceased family member. Knowing the wishes of the deceased person helped us, but it would have been far less traumatic if the decision wasn't placed in our hands.*<sup>110</sup>

Secondly, it is necessary to respect the deceased's decision who, by asking for the donor consent notation on their licence, believed it to be legal consent.

---

<sup>110</sup> Submission dated 8 June 1999. See also Australasian College for Emergency Medicine submission dated 12 June 1999.

Dr J Fisher<sup>111</sup> submitted that ‘what is ethically required is the consent of the potential donor herself or himself. It is impermissible for the family to override the known wishes of the deceased with respect to organ donation.’ Dr Fisher cites the following seven arguments in support of this:

- if people can decide to leave their body to a university and this is a matter for the individual then why should organ donation be different;
- organ donation takes place in a health care context and if people can consent to have surgical procedures done, then their consent should be able to determine whether or not to have their organs removed following brain death;
- if an executor is obliged to comply with the deceased’s wishes concerning burial or cremation ‘it is plausible to claim that the executor or next-of-kin have a similar obligation with relation to the wishes of the deceased concerning organ donation’;
- the argument is made that donation is, in effect, asking relatives to subordinate family bonds to wider societal demands and that family consent to organ donation may not be unanimous and therefore become a source of on-going family conflict. If correct, this claim provides another ‘good reason to remove the responsibility for making the decision about organ harvesting *away* from the family and to the individual concerned’;
- while there are problems associated with the concept of property rights in one’s own body, these problems do not undermine the claim that person’s have a property-like relation to their own bodies and family should not automatically have similar property-like rights in a relative’s remains;
- the family could still feel comforted by the knowledge that others will benefit from the generosity of their relative; and
- if a person cares more about not upsetting their family than they do about organ donation, they can refrain from leaving instructions that their family is to decide about organ donation.

Thirdly, the need to increase the organ donor participation rate is vital if the many people waiting for life saving transplants are to be assisted. The Queensland Renal Association Inc submitted: ‘The importance of making the driver’s licence binding and that the wishes of the individual are recognised is vital to increasing the number of organ donations and transplantation in this state’.<sup>112</sup>

#### **4.1.2 Committee analysis and comment**

Whilst the committee recognises that the submissions it received are not necessarily representative of wider community attitudes regarding the bill, the committee finds itself persuaded by the reasons provided by those opposing the proposed legislation. These highly persuasive reasons have generally been provided by people who work directly in the area of organ donation and transplantation. These workers are aware of the realities of the organ donation process and of the needs and sensitivities of a potential donor’s next-of-kin.

The committee is supportive of the general objective of the bill, namely, to increase the organ donor rate. Organ transplantation provides the only real opportunity to save or improve the lives of many Queenslanders. However, having had the benefit of wide consultation on this issue, the committee is not supportive of the manner in which the bill seeks to achieve its objective.

The bill apparently seeks to prevent relatives from stopping the organ donation process. (Although, the committee suspects that the bill as drafted might in fact continue to require—rather than prevent—hospitals consulting with a potential donor’s next-of-kin, given the proviso in

---

<sup>111</sup> Submission dated 28 May 1999.

<sup>112</sup> Submission dated 7 June 1999.

proposed section 25A(3). This proviso requires that the authorised person ‘has no reason to believe the indication is incorrect or the consent has been withdrawn’. Feasibly, satisfaction of the proviso might place a duty on hospital staff to consult with the deceased’s family.)

Essentially, the bill takes a legal approach—by giving legal effect to a driver’s licence donor consent notation—to an issue which has many other ethical, moral and social dimensions. The committee agrees with the sentiment of the Victorian Institute of Forensic Medicine (incorporating the Donor Tissue Bank of Victoria):

*The proposed amendment would strengthen the authority of those charged with collecting tissue for donation. However, clearly legislation is a blunt instrument in this context. It does not deal with the underlying ‘human factors’ which problematise the administration of the current provisions. As noted in the second reading speech, a decision from next-of-kin not to permit removal of tissue for donation, despite the deceased having indicated otherwise, can be attributed to the state of emotional distress of relatives at the time of a sudden death, or it may be that the proposed actions are in conflict with deeply held spiritual or other beliefs. In these circumstances we believe that it is too simplistic to say that ‘the acquisition of organs is good, and necessary and saves lives’. We consider that the approach mandated by the amendment lacks the flexibility required to ensure that ‘saving lives’ through organ donation does not come at the expense of increasing the trauma suffered by family of the deceased and inhibiting the grieving process necessary to recover from the loss of a beloved family member—matters which are of immediate concern to those ‘at the coalface’ of human tissue donation.<sup>113</sup>*

Organ donation must be considered from the perspective of the donor/donor’s family as well as from the perspective of the recipient and the community generally. The committee’s research and many submissions received by it make it clear that the involvement of a potential donor’s next-of-kin is an integral part of the organ donation process. The proposal in the bill clearly is at odds with what has become acceptable practice amongst tissue donation organisations.

The committee was impressed by the submission of the three donor coordinators at the Princess Alexandra Hospital (who together have 27 years experience in the area and have had contact with over 500 donor families). The donor coordinators submitted:

*It would be naive to think that enforcing a practice where a recorded document indicating a wish to donate and **excluding** the family at an emotional and devastating time for them would be ‘good practice’.*

*Experience with donor families over the years has primed us with the important information that family discussion has produced a positive outcome for all. Organ donation is often the only positive outcome for families who have suffered a sudden and tragic loss. The decision making process and the ability to carry out the last wishes of the deceased have proved to be very important in their grieving process.<sup>114</sup>*

Similar sentiments were expressed by Queensland Health officers in their meeting with the committee of 27 May 1999.

In fact, from the submissions it has received, the committee queries whether, if the bill was passed, the medical profession would be put into an uncomfortable dilemma.<sup>115</sup>

---

<sup>113</sup> Submission dated 10 June 1999, p 2.

<sup>114</sup> Ms T Cooper, Mr G Armstrong and Ms C Windle submission dated 8 June 1999, p 3.

<sup>115</sup> See also an article by D Thorp, ‘Organ recipients plead for gift of life for others’, *The Australian*, 23 January 1993, p 9 where the then federal vice-president of the AMA was quoted as saying: ‘No doctor would ever remove organs from a patient who has just died if the family is opposed to it, no matter what the law may be, no matter what the consent may be of the person’.

These ethical issues aside, it seems that, in any event, introducing a system which enforced what was recorded on a driver's licence, regardless of the wishes of the family, could *practically* result in a decline rather than an increase in the number of organ donors. In the words of another submitter, Ms M Daly, the Senior Counsellor for the Qld Donor Family Support Program: 'Families who perceived that they were poorly treated, or their wishes disregarded could become a very powerful lobby group who could generate enormous negative publicity which would harm the program'.<sup>116</sup>

For these reasons the committee cannot recommend that the Parliament support the bill in its current form. The committee notes that the bill only deals with part of one aspect of the organ donation process, that is, donor identification. Clearly, there are many other elements of the process to consider. As the submissions above indicate, addressing other hurdles to donor identification and some of the other elements in the process might be more effective in increasing Queensland's organ donation rate while still involving consultation with the deceased's next-of-kin. The committee discusses these alternative strategies further in chapter 5.

#### 4.1.3 Committee recommendation 1

**The committee recommends that the Parliament not support the Transplantation and Anatomy Amendment Bill 1998 in its current form.**

#### 4.2 A REVIEW OF THE *TRANSPLANTATION AND ANATOMY ACT*?

Finally, while it is beyond the terms of the reference of this inquiry, it appears evident to the committee that the current law regarding organ donation and transplantation (as expressed in the *Transplantation and Anatomy Act*) does not reflect the current practice of consulting with the deceased's family as a matter of course. In addition, the committee notes that the provisions regarding cadaveric organ donation (based on the 1977 ALRC report) were introduced prior to Queensland Transport allowing people to record their wish to become a donor on their licence.<sup>117</sup> (Although the committee recognises legal advice which states that a donor consent notation on a Queensland driver's licence is not sufficient written consent for the purposes of s 22(6) of the Act.<sup>118</sup>)

The Victorian Institute of Forensic Medicine (incorporating the Donor Tissue Bank of Victoria) also made the following observation in its submission:

*Since the ALRC report was written and the consequent legislation passed, there has been limited promotion and education about the benefits of tissue donation after death. There have also been significant legal and practical developments in the notion of what constitutes informed and valid consent in the context of medical procedures—developments that have made medical practitioners wary about acting where there is any hint of an objection to a procedure. In addition, the rise of the consumer movement over the last 20 years, has empowered the community to question medical paternalism and legitimised an expectation of consultation on issues affecting individual rights, such as, in the present context, rights over the disposal of remains of a deceased family member. So, despite the intention of the legislation to facilitate the collection of donor tissue, and prioritise the deceased's wishes, human factors such as the reality of next-of-kin objecting have intervened to make administration of the legislation somewhat problematic.*<sup>119</sup>

---

<sup>116</sup> Ms Daly submission dated 2 June 1999.

<sup>117</sup> Queensland Transport advises that this came into effect on 1 July 1985.

<sup>118</sup> Crown Law advice to Queensland Health dated 21 July 1998.

<sup>119</sup> Submission dated 10 June 1999.



The 1996 Brennan report similarly observed:

*Demand is growing, but the reality is that many of those waiting for organ donation will die without being transplanted. The number of donations is falling. Some of the ethical and moral issues which many had thought were behind us are re-emerging. The broader community is now more inquisitive and cynical about the health industry and health professionals. In this era of accountability professionals who work in a field which impinges on moral and ethical issues must expect to be under constant scrutiny and held accountable for their actions.*

...

*Organ and tissue donation is based on the dual pillars of tissues and organs being freely gifted and subject to informed consent of the donor and/or their family.<sup>120</sup>*

Therefore, it might be timely for the provisions regarding the donation of organs and tissue after death to be reviewed in their entirety. Given that these provisions are relatively uniform throughout Australia (and uniformity is desirable), preferably this would be a matter to be considered by all Australian Health Ministers.

The question regarding organ donation on the Queensland driver's application/renewal form might be revisited in such a review.

#### **4.2.1 Committee recommendation 2**

**The committee recommends that the Minister for Health, as the minister responsible for the *Transplantation and Anatomy Act 1979 (Qld)*, consider reviewing Part 3 of the Act (Donations of tissue after death) with the aim of establishing whether those provisions should be amended to more accurately reflect current practice in relation to organ donation and transplantation. Given the relative uniformity of these provisions in Australia (and given the desirability of maintaining that uniformity), this is a matter which the minister might wish to raise at an appropriate Australian Health Ministers' forum.**

---

<sup>120</sup> Brennan report, op cit, p 4.

## **5. SPECIFIC MEASURES TO INCREASE THE NUMBER OF ORGAN DONORS IN QUEENSLAND**

In chapter 4 the committee stated its position on the bill referred to it. However, as noted in that chapter, submissions to the committee's inquiry which did not support the bill suggested a number of alternative ways by which Queensland could seek to increase its organ donor rate.<sup>121</sup> Given the substantial amount of valuable information provided to the committee in this regard, the committee takes the opportunity in this chapter to discuss some of the suggestions that were made.

### **5.1 A COORDINATED APPROACH TO ORGAN DONATION**

Clearly, those jurisdictions which enjoy higher organ donor rates have established, and maintain, successful organ donation programs which coordinate—in a manner depending on local conditions—donor identification, screening and management; obtaining consent and necessary authorisation; and organ retrieval and allocation. (Some of the specific models were discussed in chapter 3.)

The committee has detailed in chapter 3 Queensland Health's recently established program Queenslanders Donate which combines the strengths of other models and takes account of Queensland's decentralised nature. The program seeks to maintain/increase the number of organ and tissue donors in Queensland. It does so within a framework of a structured, consistent approach to donation aimed at ensuring that the key elements of organ donation are met. Queenslanders Donate aims to be complementary to, and supportive of, the objectives of Australians Donate (also described in chapter 3).

The committee notes that Queensland Health intends to evaluate this new program (the program manager only commenced in June 1999) within 12 months to ascertain:

- whether organ/tissue donation rates have increased;
- if consent to donate organs and tissue has increased;
- the results of death audits (which seek to establish how many potential donors have been missed in the past);
- whether cost savings have been achieved through more efficient processes and the replacement of expensive artificial prostheses with human tissue (for example, heart valves); and
- whether public attitudes to organ donation have changed (by repeating the Health Information Centre survey).<sup>122</sup>

Evaluation of the program will no doubt enable Queensland Health to modify and refine the program accordingly.

The committee supports the objectives of the Queenslanders Donate initiative as a comprehensive and coordinated approach to organ donation. (The committee also notes that Queenslanders Donate is in accordance with the Member for Thuringowa's suggestion that Queensland introduce a model to increase organ donation.)

---

<sup>121</sup> While the committee refers to organ donors/donation in this chapter, the reference is intended to also include tissue donation.

<sup>122</sup> Queensland Health submission dated 22 June 1999, pp 15-16.

Submissions to the committee suggested that more specific measures might be undertaken to increase/enhance organ and tissue donation in Queensland. The committee notes that many of the specific measures would complement the Queenslanders Donate's program. The specific suggestions which the committee addresses in this chapter are:

- raising awareness of organ donation in both hospitals and the community and, in the case of the latter, encouraging people to inform their family about their decision to be an organ donor;
- ensuring that people who do consent to being a donor have sufficient information on which to base that decision;
- ensuring Queensland Health/donor coordinators can access the organ donation information on the Queensland's driver's licence database;
- establishing a national donor database; and
- maintaining adequate support measures are in place for donors' families.

## 5.2 RAISING AWARENESS ABOUT ORGAN DONATION

It has become apparent from the committee's inquiry that increasing awareness about organ donation—in the community generally and in hospitals/intensive care units specifically<sup>123</sup>—is important to lifting organ donation rates. Community understanding and acceptance of donation appears vital to increasing donation rates. Encouraging intensivists to pursue (and pursue effectively) organ donation helps to ensure that potential donors are not 'missed'.

The importance of both of these facets of education/awareness is clearly recognised by Australians Donate and Queenslanders Donate.

Many submissions to the committee likewise stressed the importance of raising awareness about organ donation. Matters which submitters felt the community should be made aware of include:

- the importance of organ donation and the potential that can accrue from just one person becoming a donor;
- the preconditions to becoming an organ donor;
- the ways in which a person can record their desire to be a donor and the importance of communicating the decision to be a donor with family (discussed further below);
- facts about the organ donation process, including that potential donors will not be allowed to die to secure organs, the difference between circulatory death and brain death and the fact that a potential donor can specify the organ and tissue they wish to donate;
- some of the problems/negative experiences of organ donation; and
- the process by which donor recipients are selected.

According to submissions, these education and awareness programs need to be: explained in simple terms; presented in a variety of media; available in multiple languages; provide people with a contact point so they can ask further questions; and be accessible through hospitals, health clinics, blood donation centres, health insurance fund offices and driver's licence centres.

---

<sup>123</sup> The Australian and New Zealand Intensive Care Society states that consideration of organ donation in brain dead patients is an 'ethical and professional responsibility of the intensive care specialist'. *Report of the ANZICS working party on brain death and organ donation: Recommendations concerning brain death and organ donation*, second edition, ANZIC, Melbourne, 1998.

The committee recognises that many such community awareness strategies are already in place. Australians Donate is responsible for public education programs at the national level.<sup>124</sup> As part of these programs, Australians Donate is currently endeavouring to provide standardised organ donation information throughout Australia.<sup>125</sup> Queenslanders Donate does/intends to conduct certain education and awareness strategies including the provision of educational material to participating hospitals and to Queensland Transport for distribution with driver's licence renewals. (The distribution of material with driver's licence applications/renewals is discussed further below.)

The importance of training hospital staff, in particular medical intensivists and ICU nursing staff, about organ donation and approaching donor families is also widely recognised in a number of organ donation models as being integral to enhancing donor rates.<sup>126</sup> Australians Donate oversees the professional education program, ADAPT, which the Brennan report recommended should be incorporated into the curriculum of postgraduate training for doctors and nurses employed in critical care areas.<sup>127</sup> Educating and increasing intensive care staff awareness of organ donation is one of the specific tasks of the link nurses employed by Queenslanders Donate.

In the case of community education, the committee envisages that the essential message to be conveyed is that transplantation saves lives, but only if people help by: (a) recording their intention to be a donor either by their driver's licence or some other means; and (b) communicating their decision to be a donor with their family.

(a) Informing people how they can record their wish to be a donor

The committee has already noted in chapter 2 the various ways in which people can record their intention to become a donor.

A number of submissions advised the committee that there is currently no capacity to indicate wishes for organ/tissue donation in an advance health directive made under the *Powers of Attorney Act 1998* and that this should be rectified.<sup>128</sup> An advance health directive (AHD) is a document created by a person (while they have the capacity) to express wishes about health matters to be followed should they subsequently become incapacitated.<sup>129</sup> A direction in an AHD only operates when the person has impaired capacity for the matter covered in the direction.<sup>130</sup>

An AHD can only cover removal of tissue from the person while they are alive. As an attorney's power ceases on the person's (principal's) death, an attorney has no power in relation to tissue donation by a deceased principal.<sup>131</sup>

The committee understands that a number of people who use AHDs do not have a driver's licence.<sup>132</sup> Therefore, AHDs could provide an additional means by which people can record their

---

<sup>124</sup> Australians Donate have a number of public and professional education programs underway (outlined in its activity report for June 1998 to January 1999). The public education program includes the operation of a national freecall 1800 information line on organ and tissue donation.

<sup>125</sup> Australians Donate stress that nationally standard information is important given Australians are mobile and organs can be provided interstate: Australians Donate submission dated 9 June 1999, p 8.

<sup>126</sup> Recent data shows that intensive care clinicians and registrars play the predominant role in requesting consent for organ donation in Australia (60%). There is a large difference between the Australian states in the role of the donor coordinator in seeking consent. ANZOD, 1999 report, op cit, p 21, figures 39-41.

<sup>127</sup> Brennan report, op cit, p 71.

<sup>128</sup> See, for example: Queensland Emergency Nurses Association Inc submission dated 11 June 1999; AMAQ submission dated 1 July 1999; St Luke's Nursing Service submission dated 10 June 1999.

<sup>129</sup> MacFarlane, op cit, p 83. *Powers of Attorney Act 1998*, s 35.

<sup>130</sup> *Powers of Attorney Act 1998*, s 36(1)(a).

<sup>131</sup> *Powers of Attorney Act 1998*, schedule 2, s 7 (definition of 'special health care').

<sup>132</sup> Information provided by Queensland Health officers to the committee in a meeting on 27 May 1999.

decision to be a donor.<sup>133</sup> Although, the committee also recognises that, to be truly effective, AHDs (like drivers' licences) will need to be on a register accessible by those involved in organ donation.

The South Australia Minister for Human Services advised the committee that in that state people can record their desire to be an organ donor in their advance directive.<sup>134</sup>

(b) Encouraging people to inform their next-of-kin about their decision to be a donor

One of the critical issues in the organ donation process is ensuring that people discuss with their family their decision to be a donor and of any change in mind that they might have.<sup>135</sup> (This is particularly so where an up-to-date donor database cannot be readily accessed by those involved in organ donation.) Knowing the deceased's wishes relieves substantial pressure from the family at a time when they are experiencing the trauma of losing a family member.<sup>136</sup> As already noted, where a family knows the deceased's wish to be a donor they are very unlikely to object to donation.

A 1995 survey found that half of the population have discussed organ donation with their family and 35% have discussed it with friends.<sup>137</sup> Queensland Health's 1998 state-wide survey found that 80% of respondents indicated that their immediate family was aware of their decision to donate. 94% of respondents indicated that they would provide consent for donation if an immediate family member died and had indicated a willingness to donate their organs. As Queensland Health stressed to the committee, this data confirms the value of encouraging discussion with family members to increase the awareness of an individual's wishes.<sup>138</sup>

There are an unlimited number of devices which may be used as a means by which familial communication about organ donation could be achieved. Without trivialising the matter, this could include merchandise such as key rings, pens, t-shirts or a separate certificate that could be kept with family legal documents (although of course the certificate must stimulate discussion when the potential donor is still alive; it is too late by the time the will is read). The purpose of all of these devices is to assist in prompting discussion about organ donation within the family at the time the decision is made.

In the case of driver's licences, more specific measures could be implemented to prompt such communication. For example:

- a family member could be required/given the opportunity to countersign the licence application where organ donation is considered,<sup>139</sup>

---

<sup>133</sup> The AMAQ also notes that AHDs could include advice as to the necessity for continued ventilation for several hours after death and a statement to the family confirming the principal's wish for organ and tissue donation. Submission dated 1 July 1999.

<sup>134</sup> Submission dated 16 June 1999. This is pursuant to the *Consent to Medical Treatment and Palliative Care Act 1995* (SA).

<sup>135</sup> This was stressed in a number of submissions to the committee. Encouraging people to speak about organ donation and transplantation and to communicate their wishes to their relatives is also seen as an integral part of the European Consensus Document *'Meeting the Organ Shortage'*, op cit, para 2.1xiii.

<sup>136</sup> For example, Mr B Abbenbroek—Australians Donate National Council Member, President of the Confederation of Australian Critical Care Nurses (NSW Branch)—advised the committee that he has seen many organs lost due to families not knowing a person's preference and then being hesitant to consent due to this uncertainty especially given the usual tragic circumstances: submission dated 31 May 1999.

<sup>137</sup> Survey conducted by Frank Small and Associates: results are from the ACCORD website <<http://www.span.com.au/span/accord/attitudes.html>> downloaded on 14 July 1999.

<sup>138</sup> Submission dated 22 June 1999, p 11.

<sup>139</sup> Mr B Abbenbroek submission dated 31 May 1999. In Victoria, next-of-kin are required to sign the donor registration form indicating that they have been consulted by the intending donor: Australians Donate, *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, Australians Donate, 7 September 1998, recommendations, p 5.

- the driver's licence application/renewal form could require a person indicating that they want to be a potential donor to state on their licence form that they have discussed their decision with their family/nominate a person with whom they have discussed their decision;<sup>140</sup> or
- state and territory registration authorities could be requested to include in driver's licence application/renewal material an encouragement to licence holders to discuss and seek endorsement from their families with respect to their wish to become an organ/tissue donor in the event of their death.<sup>141</sup>

The committee favours the third of these measures (and discusses it further in the next section). In this regard the committee agrees with an observation of Australians Donate that 'the placement of steps and obstacles in the way of a licence applicant's completion of paperwork which is primarily routine and administrative may hinder rather than promote the value of donation'.<sup>142</sup>

The suggestion was also made to the committee that AHDs would prompt the principal to discuss donation with their family and/or doctor.<sup>143</sup>

### An organ donor advocate

Mr Bill Hewitt submitted to the committee that community awareness and education could be enhanced by the appointment of an organ donor advocate.<sup>144</sup> The committee sees much benefit in having a dedicated person fill a community education/relations role throughout the state regarding organ donation. In particular, this advocate could advise people on how to record their decision to be an organ donor and stress the importance of communicating with their family their decision in this regard.

In addition to liaising with Queenslanders Donate and Australians Donate, this advocate could liaise with health care organisations, law associations (especially those involved in estate planning), educational organisations, religious organisations, donor and recipient groups, business and community organisations, the media and minority organisations.

### **5.2.1 Committee recommendation 3**

**The committee supports the efforts of Australians Donate and Queenslanders Donate to increase education and awareness about organ donation both in the community and in hospitals. In particular, the committee supports the emphasis on educating people about the importance of communicating their decision to be a donor with their family. The conduct of periodic surveys will assist in measuring the effectiveness of these efforts.**

---

<sup>140</sup> The WA Minister for Health advised the committee that in WA proposed changes to the donation consent procedure on driver's licences will require the licensee to sign a declaration that they wish to donate their organs and/or tissue and that they have made their wishes known to their next-of-kin: submission dated 24 June 1999. Ms T Cooper, Mr G Armstrong and Ms C Windle submitted that the current wording on the licence application form could ask persons to indicate whether they have told their family of their wishes: submission dated 8 June 1999.

<sup>141</sup> This is recommended by Australians Donate in *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, op cit, rec 6, p 5.

<sup>142</sup> Ibid.

<sup>143</sup> Meeting between Queensland Health officers and the committee on 27 May 1999.

<sup>144</sup> Submission dated 14 July 1999. In South Australia, a dedicated organ donor awareness and education committee comprising all groups in that state working towards promoting organ donation has been formed. The committee aims to improve the public awareness and commitment to organ donation and to integrate all organisational activities involved in organ donation and transplantation: SAODA, *Report of the activities of SAODA: July 1996/Dec 1997*, pp 9-10.

**The committee recommends that the Minister for Health consider the appropriateness and feasibility of appointing (as part of Queenslanders Donate) an organ donor advocate to further develop and promote education and awareness strategies regarding organ donation in the Queensland community.**

**To assist people in recording their decision to be a donor, the committee recommends that the Attorney-General, as the Minister responsible for the *Powers of Attorney Act 1998 (Qld)*, investigate amending that Act so as to allow people to record a wish to be an organ donor after their death in an advance health directive.**

### **5.3 ENSURING A PERSON'S INFORMED DECISION REGARDING DONATION**

Currently, people who apply for or renew their driver's licence are able to indicate a preference of 'yes', 'no' or 'undecided' in response to the question 'In the event of your death, do you consent to the removal of any body organs or tissue?'. Queensland Transport confirms that no advice or written material regarding organ donation is provided to people who apply for or renew their licence. On acceptance of the application for a driver's licence, the Queensland Transport licensing database and the licence itself is updated noting the preference of the licence holder. This procedure applies on each renewal of the driver's licence (standardly every 5 years). Queensland Transport advises that, 'Beyond this, Queensland Transport does not solicit nor correspond with clients or other agencies regarding organ donation.'<sup>145</sup>

A number of submissions to the committee reiterated that there is a need to ensure that any consent to be an organ donor—whether indicated by way of a driver's licence or otherwise—is full and informed. For example, the Knights of the Southern Cross Inc stated: 'Organ transplants are not morally acceptable if the donor, or those who legitimately speak for him, have not given their informed consent'.<sup>146</sup> Generally, submissions suggested that, to be able to provide informed consent, potential donors needed to understand what donation entailed and exactly what organs and tissue they were consenting to donate.<sup>147</sup>

At common law, a patient must give valid consent before undergoing medical treatment. Valid consent requires that a patient has the capacity to give consent, has consented in relation to the particular treatment and has freely agreed to the procedure (that is, the consent was not obtained by threats, force, coercion or unfair advantage). As an adjunct to voluntary consent, a patient must be informed in broad terms and must understand the nature of the treatment.<sup>148</sup> However, consent to undergo a medical procedure is different from a person's right to make informed decisions concerning treatment options.<sup>149</sup>

In the case of organ donation, the *Transplantation and Anatomy Act*, s 22(6) stipulates that before the deceased's consent can be acted upon it must have been expressed in 'signed writing'. There is no statutory requirement that the person must be 'fully informed' for consent to be valid.<sup>150</sup>

---

<sup>145</sup> Hon S Bredhauer MLA, Qld Minister for Transport, submission dated 11 June 1999.

<sup>146</sup> Submission dated 6 June 1999.

<sup>147</sup> A number of submitters felt that there should be an option to include/exclude particular organs and tissue to make the consent valid. 'This is all the more important as the range of organs and tissues are constantly being expanded due to advances in medical techniques': Dr C Naylor and Ms M Daly submission dated 31 May 1999, p 2.

<sup>148</sup> MacFarlane, *op cit*, p 74.

<sup>149</sup> If a patient is informed about the general nature of the treatment and consents to it then that is valid consent and they will not have an action for assault/trespass. If a health care professional fails to go into details of the risks and alternatives of treatment, this might be actionable in negligence. *Chatterton v Gerson & Anor* (1980) 3 WLR 1003 per Bristow J at 1013.

<sup>150</sup> The issue of consent for the purposes of the *Transplantation and Anatomy Act 1979*, ss 22-23 is discussed in section 2.2.2.

It is therefore not clear what standard of information, if any, must be provided to potential organ donors to further inform them or to make their consent valid. However, if the standard required in relation to medical procedures is applied, it seems that this consent should at least be informed 'in broad terms'.<sup>151</sup> The committee envisages that this means the person should understand the nature and purpose of donation, and the circumstances in which donation will take place (as defined in the Act). This means that potential donors should be provided with sufficient, accurate information on which to base their decision to be a donor. This should include the opportunity to ask and have answered any questions they might have about the donation process.<sup>152</sup>

The committee also believes that people should have a right to require amendment of the donor notation on their driver's licence because it is either incorrect or they have changed their mind.<sup>153</sup>

However, the committee believes that there it is also necessary to ensure that the amount and nature of the information provided to people thinking about becoming a potential organ donor does not unduly hinder organ donation. **In practical terms, ultimately, the deceased's family must be satisfied that the potential donor made a well-informed or considered decision regarding organ donation.**

The committee is concerned that, at present, Queensland drivers are not receiving sufficient information about organ donation at the time they apply for or renew their driver's licence. Australians Donate shares the committee's concerns.<sup>154</sup> Whilst the committee recognises that currently donor consent notations on licences are of limited usefulness (because of the restrictions on accessing that information), the committee recommends later in this chapter that this be rectified as a matter of priority.

Both Queensland Transport and Queensland Health acknowledge that information about organ donation could be included with licence application and renewal information (the latter is sent to drivers six weeks prior to the renewal date of their licence). This information could encourage people to discuss donation with their family. Queensland Transport advises the committee that it is not equipped to perform the role of further informing and educating people about organ donation via the licence process, but that Queensland Health could provide written material for potential donors in licence renewal letters and at Queensland Transport Customer Centres, and additionally provide a contact number for those who wish to discuss the matter further.<sup>155</sup>

Queensland Health also suggests that a 'freecall' phone could be provided at Transport Customer Centres to enable people to discuss any concerns or questions with qualified staff which 'would reduce the onus on counter staff to be answering donation questions'.<sup>156</sup> Other suggestions made in submissions to the committee include utilising registered nurses<sup>157</sup> and volunteer councillors

---

<sup>151</sup> The NHMRC's *Recommendations for the donation of cadaveric organs and tissues for transplantation* set out what sort of information should be provided to the family in obtaining consent or an indication of non-objection to donate organs and tissue: op cit, pp 5-8.

<sup>152</sup> See the Scrutiny of Legislation Committee comments on the bill noted above in chapter 1. Queensland Nurses Union submission dated 10 June 1999.

<sup>153</sup> The Scrutiny of Legislation Committee also recommended that, if the bill is passed, persons be given this express statutory right. See chapter 1.

<sup>154</sup> Australians Donate discussion paper *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, p 2. A Western Australian working party considered the question of the legal weight of the consent to donate on driver's licences and identified a number of concerns with driver's licence consent including: 'The ease and simplicity of ticking a box may indicate that the person did not give much thought to the issue and as such may not be sufficient indication to next of kin that the deceased wished to donate': Hon J Day, WA Minister for Health, submission dated 24 June 1999.

<sup>155</sup> Hon S Bredhauer MLA, Qld Minister for Transport, submission dated 11 June 1999.

<sup>156</sup> Queensland Health submission dated 22 June 1999, p 13.

<sup>157</sup> Queensland Nurses' Union submission dated 10 June 1999.



(perhaps retired medical practitioners at driver's licensing registries) to ensure that people understand the implications of recording a donor consent notation on their licence.<sup>158</sup>

The committee notes that in both Western Australia and South Australia donors are provided with information about organ donation with licence application and renewal information. In Western Australia this material urges potential donors to inform their family of their decision to become an organ donor.<sup>159</sup>

In a recent discussion paper *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, Australians Donate recommends that state and territory motor registration authorities:

- be approached with a view to making available, at time of offering new or renewed drivers' licences, such information as would render applicants' consent to donate truly informed;
- be offered such packaged information kits as would encourage them to ensure that counter staff are either sufficiently well informed about the process and end-value of organ donation/tissue donation as to respond to inquirer's questions, or that they are in a position to refer them to sources of information to respond to such queries; and
- agree in principle to the inclusion, in printed material supplied to applicants for new or renewed drivers' licences, information relating to organ and tissue donation developed in association with Australians Donate. (Australians Donate notes that it is possible, with the agreement of the authorities, for Australians Donate to supply such quantities of information leaflets as may be inserted in licence renewal notices, or supplied with application material.)<sup>160</sup>

The value of such initiatives should be seen in the context of the discussion in the previous chapters and below. That is, an organ donor notation on a licence can be a fundamental tool used by hospital authorities when approaching a potential donor's family. It can equally be a fundamental tool for a potential donor's next-of-kin thinking about agreeing to their family member's organ donation.

The committee believes there is a need to provide material about organ donation to Queensland drivers when they apply for and renew their licence. However, the committee does not see a need to change the current form of driver's licence cards (to state that licence holders consent more formally than at present) as the Scrutiny of Legislation Committee recommended. (Although the committee notes below that the driver's licence application/renewal form needs to be changed regarding the driver's consent to releasing information to Queensland Health.)

### 5.3.1 Committee recommendation 4

**The committee recommends that Queensland Health (continue to) liaise with Queensland Transport (and Australians Donate) about utilising the driver's licence application and renewal process to provide people with information about organ and tissue donation. This information should encourage people to communicate their decision to be an organ donor with their family and be such that it gives the potential donor's next-of-kin confidence that the potential donor has made a well-informed or considered decision about organ donation. Where appropriate, changes should be made to the *Traffic Regulations 1962* and current administrative procedures to achieve this.**

---

<sup>158</sup> AMAQ submission dated 1 July 1999.

<sup>159</sup> Hon M Criddle MLC, WA Minister for Transport, submission dated 9 June 1999. Hon D Laidlaw MLC, SA Minister for Transport and Urban Planning, submission dated 15 June 1999.

<sup>160</sup> Australians Donate, *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, *op cit*, recommendations 1, 2 and 5.

**In addition, the committee recommends that the Minister for Transport amend the *Traffic Regulations 1962* to provide licence holders with an express statutory right to require amendment of the donor consent notation on their driver's licence at any time.**

#### **5.4 IMPROVING ACCESS TO DRIVER'S LICENCE ORGAN DONATION DATA**

As noted in chapter 2, s 14A of the *Traffic Act* currently prevents the release of driver's licence information to 'another person' without the driver's written agreement. This means that organ donor coordinators and others involved in the organ donation process are unable to access the licence database to establish whether a potential donor has previously recorded a positive or 'undecided' donor notation on their driver's licence.

Access to the driver's licence database by those involved in the organ donation process is particularly important given that: (a) only a small percentage of people in an ICU have their driver's licence with them; and (b) knowing a person's preference regarding organ donation assists donor coordinators in approaching the next-of-kin and assists the next-of-kin in coming to a decision regarding donation.

A number of submitters, including Australians Donate and Queensland Health, stressed that the considerable value of driver's licence data as an indicator of donor status, is largely negated by problems of access to that data.<sup>161</sup> Queensland Health submitted:

*To assist Queensland Health to increase the rate of organ/tissue donation, Queensland Transport has been investigating new or additional mechanisms to assist people in recording their decision and to make that information available to medical practitioners when needed. The value of this information is to be able to say to family members that a relative had indicated that they did want to be a donor, or that undecided had been ticked. If a person had indicated 'no' it is still worthwhile asking the family if the person had discussed the issue with the family and had indicated their preference. It is possible for opinion to change during the 5-year period in which a licence is valid. Nevertheless, the family's final decision will always be respected.*<sup>162</sup>

Australians Donate similarly stressed that foreknowledge of a patient's donor status can be a strong determinant of whether or not donation proceeds and will have a substantial impact on donation rates.

*Such foreknowledge offers relief from the uncertainty on the part of ICU staff, donor coordinators and the donor's family about the donor's wishes, meaning that the family is relieved of the responsibility of themselves making a decision on whether or not donation may proceed, at a time of enormous emotional stress. The Committee should not underestimate the impact of this issue on donation rates. A study in Victoria indicated that where a patient's positive donor status is known at the time of declaration of 'brain death', in all cases the donor's family consented to donation. Where, however, donor status was not known, refusal rates were 39% of requests.*

*Since the actual numbers of donations are already quite small, and are thus swayed dramatically by just a handful of lost or missed donors, 39% of requests lost translates into a number of potential donors who would otherwise have saved many lives, and whose contribution to that State's donation rate would be considerable. For example, in 1998, there were 40 donors for the year in Queensland, and a donation rate of 12 donor pmp. Add 39% (in an assumption that there were as many missed donors as occurred in the Victorian*

---

<sup>161</sup> See for example: Australians Donate, submission dated 9 June 1999, pp 4-5. (In its submission, Australians Donate urged the committee to recommend such revision of driver's licence management in Queensland as will permit the release of driver's licence data regarding donor status.); Queensland Health submission dated 22 June 1999, p 12; and Royal Brisbane Hospital submission dated 18 May 1999.

<sup>162</sup> Queensland Health submission dated 22 June 1999, p 13.

*study), and the number of donors increases to 55, and the donors pmp donation rate lifts to 16 - comfortably ahead of all States except South Australia, and almost 50% higher than the national donation rate for that year (10.5 donors pmp).*<sup>163</sup>

The committee further agrees with the observation made by a number of submitters that the general public are unaware that the donor consent notation on a driver's licence is not available to those who require the information. Clearly, more needs to be done to meet the public's perception that those responsible for donation have access to the driver's licence data.<sup>164</sup>

Queensland Health notes that the legislative barriers to the release of this information could be overcome by:

- amending s 14A of the *Traffic Act* to allow the release of information to authorised medical officers for organ donation purposes;
- amending the current driver's licence application/renewal form to ask those drivers who do agree to be a donor, to also authorise the transfer of that information to Queensland Health for organ donation purposes.

The latter option, Queensland Health notes, would involve the periodic download of information from Queensland Transport to Queensland Health so that medical staff and transplant coordinators could access this information on a database.<sup>165</sup> (The Member for Thuringowa also noted in his second reading speech that, in the long term, Queensland needs an organ (donor) database.)

Queensland Transport confirms that, practically, the transfer of data to a new Queensland Health database would be the only viable option. This is because:

*Currently, organ donors are recorded in Queensland Transport's licensing database (TRAILS). This system is not available after hours or on weekends which limits its functionality as an organ donor database. One solution would be for a linkage to be created between TRAILS and a Queensland Health developed database, with appropriate batch downloads of information.*<sup>166</sup>

Queensland Transport goes on to note that the legislative impediments to accessing driver records can be overcome by amending the current driver's licence application form to reflect a donor's consent to access their record, and that Queensland Transport's role in this system would be to provide amended forms and provide database access to Queensland Health.<sup>167</sup>

In this regard, Queensland Health advises that it has been negotiating with Queensland Transport to include consent for the information to be provided to Queensland Health when consent for donation is indicated on the driver's licence.<sup>168</sup> (Queensland Health did not, in its submission, explore the information technology issues surrounding the establishment of a database, but did acknowledge that considerable resources would be required to establish and manage such a database.<sup>169</sup>)

Some other Australian states have systems in place which allow the transfer of organ donor notation data to their relevant health authorities. In Western Australia, organ donation information from the driver licensing database is downloaded to a central donor registry at the WA QEII

---

<sup>163</sup> Australians Donate submission dated 9 June 1999, p 4.

<sup>164</sup> Queensland Health submission dated 22 June 1999, p 12. Ms T Cooper, Mr G Armstrong and Ms C Windle submission dated 8 June 1999.

<sup>165</sup> Queensland Health submission dated 22 June 1999, pp 12-13.

<sup>166</sup> Hon S Bredhauer MLA, Qld Minister for Transport, submission dated 11 June 1999, p 2.

<sup>167</sup> Ibid.

<sup>168</sup> Queensland Health submission dated 22 June 1999, p 13.

<sup>169</sup> Ibid, p 16.

medical centre on a daily basis. This information can then be accessed by the State's donor coordinators. Data transferred includes full name of donor, residential address, date of birth and gender.<sup>170</sup>

In South Australia, the confidentiality provisions of the *Motor Vehicles Act 1959* (SA), s 139D and Ministerial guidelines issued under that section regulate the information about a driver which may be given out to other people and the circumstances in which it can be given. These guidelines allow information to be given to other people with the (implied) consent of the driver. A driver's nomination on the licence application form to be an organ donor is taken to be implied consent to release that information to a relevant organisation.<sup>171</sup>

However, Australians Donate notes that the inability to access databases held by licensing authorities is not unique to Queensland. With the ultimate aim of enabling a national donor database (discussed below), Australians Donate recommends that any limitations on releasing donor notation information stored on driver's licence databases be overcome.<sup>172</sup>

The committee agrees that steps must be taken to ensure that the value of driver's licence data as an indicator of donor status is not negated by denying access to that information to those involved in organ donation. This would also address the public misconception that those who require the donor notation information actually have access to it.

The committee notes that there are various options by which this can be effected. The committee also notes that Queensland Health has been negotiating with Queensland Transport to amend the current driver's licence application/renewal form to include a question asking people to consent for donor notation information to be provided to Queensland Health when consent for donation is indicated on a driver's licence. The committee urges the ministers to expedite the introduction of appropriate arrangements enabling Queensland Health to access the valuable driver's licence organ donor data.

#### **5.4.1 Committee recommendation 5**

**The committee recommends that immediate steps be taken to overcome the restrictions which currently prevent access to the donor information on the Queensland driver's licence database by those involved in organ donation.**

**In this regard the committee notes that Queensland Health has been negotiating with Queensland Transport to amend the current driver's licence application/renewal form to include a question asking people who do consent to a donor notation being recorded on their driver's licence to also consent to Queensland Transport providing that information to Queensland Health.**

**The committee urges the Minister for Transport and the Minister for Health to expedite moves to enable full use of this valuable data.**

---

<sup>170</sup> Hon M Criddle MLC, WA Minister for Transport, submission dated 9 June 1999; Australians Donate, *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, op cit, p 6.

<sup>171</sup> Hon D Laidlaw MLC, SA Minister for Transport and Urban Planning, submission dated 15 June 1999. The Minister also advises that this implied consent is strictly interpreted. The information is only given in response to an inquiry from a medical donation coordinator in a hospital about a person whose name and address or date of birth are supplied. The Registrar then confirms that the person is or is not recorded on the register of driver's licences as having indicated that he or she wished to be an organ donor.

<sup>172</sup> Australians Donate, *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, op cit, p 6.

## 5.5 ESTABLISHING A NATIONAL DONOR DATABASE

Australians Donate is currently promoting the concept of a national donor database which would aggregate donor information held on state driver's licence databases onto a national donor registry. (Obviously, Queensland would need to first develop and refine its state database in order to contribute to such a national donor database.) Australians Donate's aim is to create a single, national database capable of being accessed 24 hours a day by transplant coordinators and ICU staff.<sup>173</sup>

Such a database will not only have the advantages of a state database noted above, but will ensure that if a Queensland resident is interstate and suffers such trauma as reduces him or her to 'brain death', donor coordinators will be able to immediately establish the deceased's donor status.<sup>174</sup>

In its discussion paper, *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, Australians Donate recommends that state and territory motor registration authorities agree in principle to make available, via access mechanisms to be developed within each jurisdiction, regularly updated data on those licence holders who indicate a willingness to be noted as potential organ donors, so that a national database can be assembled and continually updated on the basis of licence data.<sup>175</sup>

Australians Donate has apparently examined a number of avenues by which this database could be established. These avenues include using a national database, National Electronic Vehicle and Driver Information System (NEVDIS), which will effectively place all driver and vehicle data onto one centralised database, or using the federal Health Insurance Commission's database. Australians Donate believes that the prospect of attaching donor status to the Commission's records gives the best possible chance for a truly national database. Australians Donate has indicated that it would welcome support in achieving this goal.<sup>176</sup>

The committee appreciates that considerable resources would be required to establish and manage a national database, and that this cost must be weighed against the benefits which might accrue. Dr Matesanz advised the committee:

*Central donor registries have been proposed by many countries..., but perhaps with the exception of a small country like Belgium, when a presumed consent approach resulted in a transient increase, many years ago, no other positive results have been obtained. Besides the development and maintenance of such a registry is expensive...*<sup>177</sup>

The committee also notes that different considerations apply in a country such as Australia given its size, and multi-cultural and federal nature. The committee imagines that Australians Donate is in the best position to ascertain the likely benefits of a national database and whether those benefits outweigh the database's establishment and maintenance costs. Utilising an existing database, such as the Health Insurance Commission database, will no doubt reduce cost.

---

<sup>173</sup> Submission dated 9 June 1999. See also Australians Donate, *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, op cit.

<sup>174</sup> One submission also noted that a national database might also allow more exact consents to be maintained (by recording specifically which organs/tissue a person wishes to donate) and permit regular checks with potential donors to ensure that their information is up to date: Victorian Institute of Forensic Medicine incorporating the Donor Tissue Bank of Victoria submission dated 10 June 1999. Of course, the same reasoning could also apply with respect to a state database.

<sup>175</sup> In its submission Australians Donate recommends that the Queensland Government support the introduction of a national donor database by removing legal and operational obstacles to its introduction and use: submission dated 9 June 1999, p 3.

<sup>176</sup> Australians Donate submission dated 9 June 1999, pp 5-6. Letter from Mr B Lindsay, National Director, Australians Donate to the committee dated 28 June 1999.

<sup>177</sup> Submission dated 7 June 1999.

### 5.5.1 Committee recommendation 6

**The committee recommends that Queensland Health attempt to ascertain the viability of the Australians Donate proposal to establish a national donor database and support that proposal should Queensland Health consider it viable. (In this regard the committee notes that Queensland Health is represented on the National Council of Australians Donate.)**

### 5.6 ESTABLISHING/MAINTAINING SUPPORT PROGRAMS FOR DONORS' FAMILIES

Whilst the issue of support for donors' families is beyond the committee's consideration of the bill and ways to increase organ donor rates, it is obviously an essential part of a successful donation process.<sup>178</sup> A number of submissions to the committee's inquiry stressed the need to support, and recognise the contribution of, donor families. Ms M Daly, Senior Counsellor for the Qld Donor Family Support Program, submitted:

*Support programs for families who have consented to donation are a way of recognising the unique gift they have given. Public acknowledgment via events like the "Annual Ecumenical Service of Thanksgiving" are also highly valued by donor families and increase the feeling of goodwill regarding organ/tissue donation programs.*<sup>179</sup>

SAODA operates from a 'shop front' office in Adelaide's central business district, rather than from a hospital. This, the agency says, is to 'maximise support for donor families' who might be reluctant to return to the hospital in which their relative has died. This office allows donor families to call in at any time and enables the community to easily access information on organ donation.<sup>180</sup>

SAODA also makes available multi-lingual bereavement counsellors at no cost to relatives. Other support available to donor families include: organising for family members to view the body after donation; regular contact following the donation; a support group called GIFT (given in faith and trust); a loss and grief workshop for donor families; a yearly thanksgiving service and dinner; and otherwise providing as much follow-up support as is required.<sup>181</sup>

Queenslanders Donate also incorporates a designated social worker to provide follow-up for donor families and offer bereavement support. This is over and above donor coordinators providing support and follow-up to donor families (and the hospital staff involved in the donation process).<sup>182</sup>

In addition, the issue of contact between the donor family and the recipient was raised in a number of submissions (including those from donor families).<sup>183</sup> The Doctors Reform Society of Queensland submitted:

*When desired, greater contact between donor and recipient families should be enabled. Families of donors should have access to information about how the organs have been used. This may result in more positive stories in the community regarding transplantation.*<sup>184</sup>

---

<sup>178</sup> Dahlenburg and Herbertt, *Annual report of the activities of the South Australian Organ Donation Agency 1998*, op cit, p 5.

<sup>179</sup> Submission dated 2 June 1999.

<sup>180</sup> Dahlenburg and Herbertt, *Annual report of the activities of the South Australian Organ Donation Agency 1998*, op cit, p 15.

<sup>181</sup> Ibid, pp 15-16. SAODA provides these services by contract with an independent counselling service which, the committee understands, frees up donor coordinators and enables donor families to freely voice opinions and problems regarding the system.

<sup>182</sup> Ms T Cooper, Mr G Armstrong and Ms C Windle submission dated 8 June 1999.

<sup>183</sup> For example: Ruth Friend submission dated 8 June 1999; and Wendy and Dale Nichols submission dated 6 June 1999.

<sup>184</sup> Submission received 8 June 1999.

The *Transplantation and Anatomy Act* makes it an offence for certain persons involved in the organ donation process to publicly disclose the identity of an organ donor or recipient.<sup>185</sup> However, Queensland Health advises the committee that it is currently evaluating a draft policy developed by the transplant coordinators at the Princess Alexandra Hospital concerning the complex issue of donor family and recipient contact. The proposed model is apparently similar to that for parties involved in adoption, that is, future contact requires consent from both parties.<sup>186</sup> The committee notes that SAODA has also recently requested the South Australian government to amend that State's *Transplantation and Anatomy Act* to allow contact between donor families and the recipients of organs, along the lines of the adoption model.<sup>187</sup>

### 5.6.1 Committee observation

**The committee notes the importance of supporting donor families and recognising the gift given by them as part of any donation program.**

**The committee also notes the donor family support programs currently in place and Queensland Health's work on a policy regarding the complex issue of contact between donor families and recipients. The committee presumes that, as part of the current evaluation of this policy, the Minister for Health would monitor the need for any legislative framework to enhance the relationship between donor families and donor recipients, particularly where it might improve the future prospect of organ donation.**

---

<sup>185</sup> *Transplantation and Anatomy Act*, s 49. Section 49(2) lists the persons to whom the section applies (generally those health workers involved in the organ donation process). Disclosure of identifying information is permissible unless the person who discloses the information is caught by the section. Whilst, in theory, this might allow the donor family and recipient to reveal their identity to each other, practically the disclosure of identifying information can only be achieved by communication with the transplant coordinator or health worker involved in the transplantation procedure. Therefore, they are probably caught by s 49(2). The members of donor families are not listed in s 49(2). Therefore, they are not bound by the confidentiality requirement. Crown Law advice to Queensland Health dated 21 July 1998.

<sup>186</sup> Queensland Health submission dated 22 June 1999, p 16.

<sup>187</sup> Letter dated 12 May 1999 from Prof G Dahlenburg to Hon Dean Brown, Minister for Human Services.

## **6. CONCLUSION**

The committee endorses the broad objective of the Transplantation and Anatomy Amendment Bill, that is, to increase organ donor rates in Queensland. There is a great potential to save lives and benefit others through organ donation.

However, the committee believes that the bill, in practice, would not succeed in achieving its objective and that, regardless, there are better ways to achieve the objective. The bill seeks to give legal effect to the donor consent notation on a driver's licence which would remove the need to consult with the deceased's relatives regarding donation. In essence, the bill links the shortage of organs with the need to consult with families.

Yet the organ donation process involves a number of steps, all of which must be considered in light of legal, medical, ethical, social and moral considerations. Of particular concern to the committee is that the proposal ignores that there are sound, ethical and practical reasons why hospitals always consult with the deceased's family about donation. In addition, the proposal does not take into account that:

- driver's licences are of limited value in that: the Queensland licence database is currently not accessible by donor coordinators; very few people actually have their licence with them when they are brought to an ICU; and, in any case, licences are not always a reliable indicator of consent;
- there are many other reasons (apart from the family refusing to consent) why potential donors do not become actual donors;
- where the family do know that the deceased has consented to organ donation they are unlikely to object to donation proceeding; and
- even if a donor consent notation on a licence was made legally binding, it would not eliminate the need for the hospital to consult with the family to establish whether the deceased's consent had been withdrawn or to establish the deceased's social and medical history.

Indeed, the committee believes that rather than increasing donor numbers, the proposal in the bill, if implemented, might have the opposite effect.

Instead, the committee's research reveals that the bill's objectives can be achieved by implementing more appropriate strategies. The private member in his second reading speech urges Queensland to introduce a model designed to increase the number of organ donors and to educate Queenslanders that the acquisition of organs is 'good, necessary and saves lives'. Steps have since been undertaken in this regard by Queensland Health through its recently-established program, Queenslanders Donate. This program is designed to be complementary to and supportive of Australians Donate, the new national body responsible for increasing national donor rates.

In addition, in chapter 5, the committee suggests that the following might assist Queenslanders Donate and Australians Donate to increase organ donation rates:

- appointing (as part of Queenslanders Donate) an organ donor advocate to further develop and promote education and awareness strategies regarding organ donation in the Queensland community (in addition to maintaining current programs which seek to educate and increase hospital staff awareness about organ donation);
- enabling people to provide for organ donation in advance health directives;



- providing Queensland drivers with more information about organ donation by utilising the driver's licence application and renewal process (and amending the *Traffic Regulations* to provide licence holders with an express statutory right to require the amendment of the donor notation on their licence);
- expediting steps to overcome the current restrictions on Queensland Health accessing the organ donation information on the Queensland Transport driver's licence database; and
- monitoring the viability of a national donor database.

The committee believes that implementation of such specific suggestions in the context of Queensland's newly-established organ donation program will, in the short and long term, be far more effective and acceptable.

## REFERENCES

### MONOGRAPHS

- Australia. Health Ministers' Advisory Council, *Review of Australian Coordinating Committee on Organ Registries and Donation*, conducted by Dr P J Brennan et al, September 1996.
- Australia. National Health and Medical Research Council, *Donating organs after death: Ethical issues*, Ethical issues in organ donation discussion paper no 1, AGPS, Canberra, 1997.
- Australia. National Health and Medical Research Council, *Ethical issues in donation of organs or tissues by living donors*, Ethical issues in organ donation discussion paper no 2, AGPS, Canberra, 1997.
- Australia. National Health and Medical Research Council, *Ethical issues raised by allocation of transplant resources*, Ethical issues in organ donation discussion paper no 3, AGPS, Canberra, 1997.
- Australia. National Health and Medical Research Council, *Certifying death: The brain function criterion*, Ethical issues in organ donation discussion paper no 4, AGPS, Canberra, 1997.
- Australia. National Health and Medical Research Council, *National statement on ethical conduct in research involving humans*, AGPS, Canberra, June 1999.
- Australia. National Health and Medical Research Council, *Recommendations for the donation of cadaveric organs and tissues for transplantation*, AGPS, Canberra, 1996.
- Australian and New Zealand Intensive Care Society, *Report of the ANZICS working party on brain death and organ donation: Recommendations concerning brain death and organ donation*, second edition, ANZICS, Melbourne, 1998.
- Australia and New Zealand Organ Donation Registry [Herbertt K and Russ GR (eds)], *ANZOD Registry 1999 Report*, Adelaide, 1999.
- Australia and New Zealand Organ Donation Registry [Herbertt K and Russ GR (eds)], *ANZOD Registry 1998 Report*, Editors:, Adelaide, 1998.
- Australian Law Reform Commission, *Human Tissue Transplants*, Report no 7, AGPS, Canberra 1997.
- Australians Donate, *Listing of organ/tissue donors on drivers' licences: Discussion paper on 'the next step'*, Australians Donate, 7 September 1998.
- Australians Donate, collation of abstracts of papers presented at the *Inaugural national forum on organ and tissue donation*, 12-13 April 1999, Canberra, 1999.
- Bates, P W and Dewdney, J C, *Australian Health and Medical Law Reporter*, CCH Australia Limited, Sydney, 1998.
- Easten, R, *A question of consent? The Transplantation and Anatomy Amendment Bill 1998*, Research bulletin 1/99, Queensland Parliamentary Library, Brisbane, February 1999.
- Queensland. Department of Health (MacFarlane P J M), *Health Law Handbook*, 9<sup>th</sup> edition, Queensland Department of Health, Brisbane, 1999.
- Queensland. Queensland Health, Health Information Centre, *Statewide Health Survey, Attitudes to Donation*, Queensland Health, April-July 1998.
- Queensland. Parliament. Scrutiny of Legislation Committee, 'Transplantation and Anatomy Amendment Bill 1998', *Alert Digest*, No 10 of 1998, tabled 17 November 1998.
- Queensland. Parliament. Scrutiny of Legislation Committee, 'Transplantation and Anatomy Amendment Bill 1998', *Alert Digest*, No 1 of 1999, tabled 2 March 1999.
- South Australian Organ Donation Agency (Dahlenburg, G and Herbertt, K), *Annual report of the activities of the South Australian Organ Donation Agency 1998*, SAODA, 1998.

South Australian Organ Donation Agency, *Report of the activities of SAODA: July 1996 - December 1997*, SAODA, 1997.

#### **ARTICLES**

Albert, P, 'Direct contact between donor families and recipients: Crisis or consolation?', *Journal of Transplant Coordination*, vol 8, no 3, September 1998, pp 139-144.

Dahlenburg, G and Herbertt, K, 'State organ donation activity update (South Australia)', abstract of paper presented at the *Inaugural national forum on organ and tissue donation*, 12-13 April 1999, Canberra, 1999.

Fisher J, 'Give and let live: Organ donation in Australia', *Proceedings of the Third Annual Conference of the Australian Association for Professional and Applied Ethics held in Wagga Wagga in October, 1996*, Keon Publications, NSW, 1997.

Holt, A W, Hodgeman, G K, Vedig, A E and Heard, P E, 'Organ donor index: A benchmark for comparing hospital organ donor rates', *Medical Journal of Australia*, vol 170, May 1999, pp 479-481.

Matesanz, R and Miranda, B, 'The Spanish experience in organ donation', in Chapman, J R, Deirhoi, M and Wight, C (eds), *Organ and tissue donation for transplantation*, Oxford University Press, New York, September 1997, pp 361-372.

Pearson, I Y and Chapman, J R, 'Improving organ donor rates', *Medical Journal of Australia*, vol 170, May 1999, pp 463-464.

#### **INTERNET ARTICLES**

Australia and New Zealand Organ Donation Registry at  
<<http://www.anzdata.org.au/ANZOD/Updates/anzodsummary.htm>>.

Australian Coordinating Committee on Organ Registries and Donation (ACCORD) at  
<<http://www.span.com.au/span/accord/donate.html>>  
<<http://www.span.com.au/span/accord/factsheet.html>>  
<<http://www.span.com.au/span/accord/attitudes.html>>  
<[http://www.span.com.au/span/accord/factsheet\\_tissue.html](http://www.span.com.au/span/accord/factsheet_tissue.html)>  
<<http://www.span.com.au/span/accord/17newsletter.html>>  
<<http://www.span.com.au/span/accord/19newsletter.html>>

Australian New Zealand Intensive Care Society (ANZICS), 'Newsletter', vol 4, no 1, 1998 at  
<<http://anzics.herston.uq.edu.au/news/NEWS9806.htm>>.

Gateway Information Facility for Transplant Services (GIFTS), 'Issues and opportunities for increased organ donation' at <[http://www.gwfs.bc.ca/gifts/art\\_001.htm](http://www.gwfs.bc.ca/gifts/art_001.htm)>.

New South Wales Red Cross at <[http://www.organ.redcross.org.au/f\\_stats.html](http://www.organ.redcross.org.au/f_stats.html)>.

'The Spanish and South Australian systems for organ donor procurement' at  
<<http://www.multiline.com.au/~donor/spain2.html>>.

United States. Department of Health and Human Services at <<http://www.organdonor.gov/opo.htm>>  
<<http://www.organdonor.gov/news/press/990416.html>>.

Victoria. Organ Donor Registry at <<http://www.dhs.vic.gov.au/organ/organ.html>>.

#### **NEWSPAPER ARTICLES**

'Donor organs "taken without family consent"', *The Courier Mail*, 6 March 1995, p 7.

Robotham, J, 'Push to increase organ donor levels', *The Age*, Monday, 12 April 1999, p 6.

Thorp, D, 'Organ recipients plead for gift of life for others', *The Australian*, 23 January 1993, pp 9 and 20.

## APPENDIX A SUBMISSIONS RECEIVED

	SUBMISSION RECEIVED FROM
1	Queensland Bioethics Centre
2	Dr I S Wilkey (Royal Brisbane Hospital and District Health Service)
3	Heart Foundation of Australia
4	Mrs Phyl den Ronden [Citizens Against Road Slaughter Inc. (CARS)]
5	Mr Colin den Ronden [Citizens Against Road Slaughter Inc. (CARS)]
6	Dr Josie Fisher (University of New England)
7	Dr Charles Naylor and Ms Michelle Daly (John Tonge Centre for Forensic Sciences)
8	Dr Peter de Jersey (Townsville General Hospital)
9	Ms Michelle Daly
10	Doctors Reform Society of Queensland Inc.
11	Mr B Abbenbroek (Australians Donate National Council Member)
12	Mr D and Mrs W Nichols
13	Knights of the Southern Cross (Qld) Incorporated
14	Ms Ruth Friend
15	Queensland Renal Association Incorporated
16	Australians Donate (and the South Australian Organ Donation Agency)
17	Victorian Institute of Forensic Medicine, incorporating the Donor Tissue Bank of Victoria
18	Ms T Cooper, Mr G Armstrong and Ms C Windle (Donor Coordinators, Princess Alexandra Hospital)
19	CONFIDENTIAL
20	St Luke's Nursing Service
21	Prince Charles Hospital and District Health Service (Ms M Haire, Director Social Work Services)
22	Professor N Thomson (Chairman, Victorian Coordinating Committee on Organ Donation)
23	Princess Alexandra Hospital and District Health Service, Renal Transplant Unit (Dr C Hawley and Dr D Nicol)
24	New South Wales Transplant Advisory Committee, Australian Red Cross Blood Service
25	The Salvation Army (Australian Eastern Territory)
26	Mrs Suzanne Savage
27	Queensland Nurses' Union
28	Prince Charles Hospital and District Health Services (Mr P Sheedy)
29	Queensland Health
30	Friends of the Donor Tissue Bank of Victoria
31	Minister for Transport and Urban Planning, South Australia (The Hon Diana Laidlaw MLA)
32	Minister for Human Services, South Australia (The Hon Dean Brown MP)

	<b>SUBMISSION RECEIVED FROM</b>
33	Australasian College for Emergency Medicine
34	Dr Rafael Matesanz
35	Minister for Transport and Minister for Main Roads (Hon Steve Bredhauer MLA)
36	Minister for Urban Services, ACT (Hon Brendan Smyth MLA)
37	Minister for Health and Human Services, Tasmania (Hon Judy Jackson MHA)
38	Minister for Transport, Western Australia (Hon Murray Criddle MLC)
39	Department of Health and Community Care, ACT (Dr Shirley Brown)
40	Minister for Roads and Ports, Victoria (Hon Geoff Craige MLC)
41	Minister for Health and Minister for Aged Care, Victoria (Hon Rob Knowles MLC)
42	Minister for Health, Western Australia (Hon John Day MLA)
43	Minister for Health, New South Wales (Hon Craig Knowles MP)
44	Ms K Mahoney
45	Mr J A Arnel
46	Mrs M C Ramsden
47	Federal Minister for Health and Aged Care (Hon Dr Michael Wooldridge MP)
48	South Eastern Sydney Area Health Service, Organ and Tissue Donation Coordination Committee
49	Minister for Infrastructure, Energy and Resources, Tas (Hon Paul Lennon MHA)
50	North Western Adelaide Health Service
51	Queensland Emergency Nurses Association Inc.
52	Mr B Hewitt
53	Queensland Branch of Australian Medical Association

