

NSW Council for Civil Liberties
Background Paper

**Organ Donation and
'Veto Rights' of Family**

Background Paper 2005/1
January 2005

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Terms of Reference

The purpose of this document is to inform debate in the Civil Rights sub-committee of the NSW Council for Civil Liberties. The issue raised for discussion is whether others should have a veto an individual's explicit wish to donate their tissues upon their death?

1. introduction

1. All Australian states and territories have laws governing the removal of human organs and tissue from a dead person for transplantation into the body of a living person (or for other therapeutic, medical or scientific purposes). The laws are based on the recommendations of the Australian Law Reform Commission's 1977 inquiry and report into human tissue transplantation.¹
2. In New South Wales, the *Human Tissue Act*² governs organ and tissue donation from deceased donors in two circumstances:
 - (i) **deceased has consented, in writing prior to death, to removal**
This situation is the subject of this paper.
 - (ii) **family of deceased consents in writing**
This situation arises when the deceased leaves no written consent, but senior next-of-kin gives such consent.³
3. This paper only deals with the first circumstance. Written consent can be given by indicating consent on a NSW drivers' licence form, by registering with the National Organ Donation Register or by some other valid written document.
4. Consent (of the deceased or next of kin) is always required for organ donations from deceased persons in NSW.⁴ As the Health Minister recently stated in Parliament:⁵

...tissue may only be removed for donation according to the written consent or wish of the deceased, given whilst alive, or where a senior next of kin gives written consent.
5. In NSW, the Coroner has, in appropriate circumstances, a veto power over organ and tissue removal from deceased persons.⁶
6. There is also a genuine public interest in people donating organs. The demand for donated organs far outweighs the supply. Donated organs and tissue save lives and help to improve the quality of life of donees.

¹ Australian Law Reform Commission, *Human Tissue Transplants* (1977) Report No. 7, <<http://www.austlii.edu.au/au/other/alrc/publications/reports/7/>>. **Note:** NSWCCCL made a submission to this inquiry.

² *Human Tissue Act 1983* (NSW).

³ see [14] for more information.

⁴ prior to November 2003, hospital staff were able to authorise organ and tissue removal from a deceased person when no next-of-kin could be identified. In response to the 2001 inquiry and report of Brett Walker SC into practices at the Glebe Morgue (<<http://www.health.nsw.gov.au/pubs/i/forensic/pdf/pmreport.pdf>>), this power was revoked by Parliament: *Human Tissue and Anatomy Legislation Amendment Act 2003* (NSW).

⁵ NSW, *Parliamentary Debates*, Legislative Assembly, 23 October 2002 (Mr Knowles, Minister for Health).

⁶ see "coronial veto" on page 7.

7. Only about 1% of people die in the extremely rare circumstances that enable their organs to be donated:⁷

With the exception of the cornea of the eye, organs are generally unusable after a person has been dead for more than 3 ½ minutes, because of the effect of lack of oxygen. This means that in practical terms organs can usually only be donated by a person who dies in hospital after being on a life support system. People killed in car accidents are usually taken directly to the morgue.

⁷ Redfern Legal Centre, *The Law Handbook* (2002, 8th ed) 1064. See also: AHIC, Australian Organ Donor Register, *Frequently Asked Questions*, n 35.

2. organ removal with deceased's consent

8. This section examines the legal and ethical dimensions of this issue separately and then discusses the interaction between the two.

2.1 the law in NSW

9. In New South Wales, the lawful removal of human organs and tissue from a dead person for transplantation into the body of a living person (or for other therapeutic, medical or scientific purposes) is governed by the *Human Tissue Act*.⁸
10. Legally, the removal of tissue from a deceased person is always subject to the terms and conditions of the consent.⁹ For example, if a donor only nominates their heart for removal, then only their heart may be lawfully removed.
11. Consent, under the Act, can only be given for removal of tissue for the purposes of:
- (a) transplantation to the body of a living person; or
 - (b) use for other therapeutic, medical or scientific purposes.

2.1.1 removal of tissue at a hospital

12. When an adult dies in a hospital,¹⁰ or when a recently deceased adult is brought into a hospital, written authority for the removal of tissue from that deceased adult *may* be issued by a 'designated officer' appointed by the hospital.¹¹
13. Before issuing any written authority the designated officer must make 'such inquiries as are reasonable in the circumstances' and be satisfied that:¹²
- 1. the deceased person had, when living, given *written* consent to the removal (after their death) of organs or tissue for the purpose of:
 - (a) its transplantation to the body of a living person; or
 - (b) its use for other therapeutic, medical or scientific purposes;*and*
 - 2. that the deceased's consent had not been revoked

⁸ [Human Tissue Act 1983](#) (NSW).

⁹ *Human Tissue Act 1983* (NSW) ss 23(1) & 24(2).

¹⁰ if a person is on life support at a hospital, then two senior medical practitioners must certify in writing that they examined the deceased on that life support and that, in their opinion, 'irreversible cessation of all function of the person's brain had...occurred': *Human Tissue Act 1983* (NSW) s 26. In other words, the donor must be certified 'brain dead'. It is an offence to fail to obtain this written certification, attracting a maximum penalty of six months imprisonment, a \$4,400 fine or both.

¹¹ *Human Tissue Act 1983* (NSW) ss 5 (appointment of designated officers) & 23 (authority to remove tissue where body of deceased at a hospital).

¹² *Human Tissue Act 1983* (NSW) s 23(1).

14. The requirement to ensure that the written consent has not been revoked necessitates consultation with, presumably, relatives and/or friends of the donor.
15. If the deceased person is a child, or if the designated officer is not satisfied that the deceased gave *written* consent for tissue donation, then the procedure requires consultation with close relatives.¹³ For the purposes of consultation, relatives are ranked in a hierarchy.
16. In the case of a deceased child, the hierarchy is, in descending order: a parent, an adult sibling or a current guardian.¹⁴ In the case of an adult deceased, the descending hierarchy is: current spouse (of the same or opposite sex), an adult child of the deceased, a parent of the deceased, or an adult sibling of the deceased. The role of next-of-kin can be delegated in writing to another person, who will then hold the same position in the hierarchy as the delegator.¹⁵
17. In such cases, written authorisation *may* be given for the removal of the deceased's tissue if, after 'making such inquiries as are reasonable in the circumstances', the designated officer is satisfied that:¹⁶
 - (a) the deceased person, when living, had not expressed an objection to the removal of tissue from their body; *and*
 - (b) the 'senior available next of kin' has consented to the removal, either in writing or their verbal consent has been electronically recorded;¹⁷ *and*
 - (c) no next-of-kin of equal or superior rank objects to the removal.
18. This means that, legally, the *written* consent of a deceased adult donor trumps the wishes of living relatives – even a spouse. However, while the Act grants designated officers the power to authorise removal of tissue, it does not make such authorisation mandatory. The designated officer is still free to make a decision contrary to the express written wishes of the deceased for the removal of their tissue.
19. Finally, as the NSW Health Department notes,¹⁸ a decision made by a designated officer under the Act is a legally reviewable decision.¹⁹ This means that a disgruntled family member might theoretically be able to seek judicial review of a designated officer's decision to authorise, or not to authorise, removal of organs.

¹³ *Human Tissue Act 1983* (NSW) s 23(3).

¹⁴ *Human Tissue Act 1983* (NSW) s 4 ('senior available next of kin').

¹⁵ *Human Tissue Act 1983* (NSW) s 5A.

¹⁶ *Human Tissue Act 1983* (NSW) s 23(3).

¹⁷ *Human Tissue Regulations 2000* (NSW) r 14A (verbal consent must be electronically recorded).

¹⁸ NSW Health, Discussion Paper, *Organ and Tissue Donation and Use and Post Mortem Examination* (October 1999) 17, fn 17. Available at <<http://www.health.nsw.gov.au/csd/l/sb/organ/issuespaper.pdf>>.

¹⁹ *Human Tissue Act 1983* (NSW) does not grant the NSW Administrative Decisions Tribunal jurisdiction to review the merits of decision made under the Act: see [Administrative Decisions Tribunal Act 1997](#) (NSW) s 8. However, judicial review of administrative decisions by a

2.1.2 removal of tissue other than at a hospital

20. If the body of a deceased adult is at a place other than a hospital, removal of tissues is *automatically* authorised if the deceased person, when living, gave their *written* consent and had not revoked that consent.²⁰ Though the Act does not expressly require it, it would be advisable to make all reasonable inquiries of family and friends of the deceased to determine whether the written consent had been revoked.
21. If there is no written consent from the deceased, then a 'senior available next-of-kin',²¹ after 'making such inquiries as are reasonable in the circumstances', *may* authorise, in writing, or verbally if electronically recorded,²² the removal of tissue from the deceased's body if they are satisfied that:²³
- (a) the deceased person, when living, had not expressed an objection to the removal of tissue from their body; *and*
 - (b) no next of kin of equal or superior rank objects to the removal.

2.1.3 coronial veto

22. In New South Wales, the coroner has a veto over organ and tissue removal from deceased persons, but only if the coroner has the power to hold an inquest into the death of that person and only to the extent that the intended removal would interfere with the coronial inquest.²⁴ Generally speaking, the coroner has the power to hold an inquest when a death is violent, unnatural, suspicious or the result of a recent medical procedure.²⁵
23. If the coroner has the power to hold an inquest into the death of the accused, then a designated officer or senior available next-of-kin must obtain the written or verbal consent of the coroner before authorising the removal of tissue from the deceased's body.²⁶ The maximum penalty for failing to obtain the consent of the coroner is 6 months imprisonment, a \$4,400 fine or both.

state's Supreme Court is still available at administrative law: see Roger Douglas, *Administrative Law* (2002, 4th ed) 334 & 336.

²⁰ *Human Tissue Act 1983* (NSW) s 24(1).

²¹ for definition of 'senior available next-of-kin', see [16] & fn 14.

²² *Human Tissue Regulations 2000* (NSW) r 14A (verbal consent must be electronically recorded).

²³ a relative who authorises removal contrary to these conditions faces a fine of \$1,100: s 24(4).

²⁴ *Human Tissue Act 1983* (NSW) s 25.

²⁵ *Coroners Act 1980* (NSW) s 13.

²⁶ *Human Tissue Act 1983* (NSW) s 25(2).

2.1.4 lawful written consent

24. In order for the objections to removal voiced by close relatives to be disregarded, the deceased's consent to removal must be in writing. There are several ways to do this. While a simple explicit document (like a will) is sufficient, the most effective way is for a donor to record their intention on their drivers licence or to register with the Australian Organ Donor Register.
25. The NSW drivers licence form allows applicants to consent either to the removal of organs and tissue, or to the removal of specific organs (kidneys, corneas, liver, pancreas, skin, bone, heart and lungs).²⁷ The form also allows people to record officially their refusal to donate organs or tissue. Donors also undertake to advise their next-of-kin of their decision.
26. In 2000, the Australian Organ Donor Register was established.²⁸ Over 5 million Australians have signed on to the Register.²⁹ Approximately 2.4 million NSW citizens have registered (about 36% of the total population).³⁰ The Register is administered by the federal Health Insurance Commission. It is a voluntary register and records people's 'intent to donate any suitable organs and tissue for transplantation', as well as which organs they want to donate (bone, corneas, heart, heart valves, kidneys, liver, lungs, pancreas, skin or all of the above). Australians can also register their wish not to donate. The information stored in the Register can, at the appropriate time, be accessed by authorised medical staff and next-of-kin. Registration can be performed online, toll-free over the phone (1800 777 203) or by filling in a form available from Medicare offices.
27. The Australian Organ Donor Register has been working with state-based Road Transport Authorities to have the latter's organ donor data transferred into the national Register. A pilot scheme is currently running in NSW.³¹

²⁷ see <http://www.rta.nsw.gov.au/publicationsstatisticsforms/downloads/formsforms_dl1.html>.

²⁸ see HIC, <http://www.hic.gov.au/yourhealth/our_services/aaodr.htm>.

²⁹ see HIC, <http://www.hic.gov.au/yourhealth/our_services/aaodr.htm>.

³⁰ see HIC, <http://www.hic.gov.au/providers/health_statistics/statistical_reporting/aodr.htm>.

³¹ NSW RTA, *Organ Donation* <<http://www.rta.nsw.gov.au/licensing/organdonation.html>>.

2.2 the law in North America

28. Australia and New Zealand have, generally-speaking, followed the English model of treating the deceased's consent as a starting point, not an end point.³² But there are other models. The situation is very different in North America.
29. In Canada, the individual provinces have responsibility for regulating organ donation. The *Uniform Human Tissue Gift Act* allows a person over the age of 19 to consent to organ and tissue removal in writing, or orally in the presence of two witnesses during their last illness. After death such consent is binding and full authority for the removal of tissue according to the terms of the consent.³³
30. In US, similar uniform national laws exist. For example, in New York state any 18 year old of sound mind may give written authorisation to post-mortem organ donation, and relatives cannot veto that authorisation 'except upon showing that the donor revoked the authorization'.³⁴

³² see ALRC, *Human Tissue Transplants* (1977), n 1, chapter 7.

³³ e.g. [Human Tissue Gift Act 1996](#) (BC) s 4.

³⁴ [Public Health Law](#) (NY) Article 43, §4301.

2.3 medical ethics and hospital practice

31. While the law permits hospital authorities to remove organs from deceased consenting donors despite the wishes of close relatives, it is nevertheless widely considered a part of ethical medical practice that hospital staff not proceed with organ removal if close family members object – irrespective of the wishes of the deceased donor.³⁵
32. This practice was explained in a discussion paper released by the NSW Health Department during a recent review of the *Human Tissue Act* (footnotes omitted).³⁶

Concerns have frequently been raised with the Department regarding the ability of a potential donor's relatives to "override" the consent or wishes of the deceased. These concerns arise as a result of the universal practice of hospitals of consulting relatives in relation to the donation of tissue by a deceased person. Where relatives are available, it is likely (depending on the circumstances of the case) that the designated officer is legally obliged to make inquiries with them as to whether the deceased withdrew an express wish to donate or revoked a consent. However, where a relative's objections are personal and do not go to the revocation or withdrawal of a wish or consent by the deceased, [the Act] does not specifically require them to be taken into account.

However, over and above the requirements of the law, hospital staff will generally feel ethically obliged to discuss and explain tissue donation procedures with relatives. Where a designated officer is faced with the knowledge that removal of tissue from a deceased person (even when they have given consent in their lifetime) will cause significant distress and even psychological harm to a family, he or she may feel that he or she is ethically, if not legally, obliged to take this into consideration when exercising his or her discretion to authorise removal.

³⁵ Australian Health Insurance Commission, Australian Organ Donor Register, *Frequently Asked Questions*, <http://www.hic.gov.au/yourhealth/our_services/aodr/fags.htm>. See also: Legal Information Access Centre, *Death and inheritance* (1999), available at <<http://www.austlii.edu.au/au/other/liac/hot%5ftopic/hottopic/1999/4/5.html>>.

³⁶ NSW Health, *Organ and Tissue Donation and Use and Post Mortem Examination*, n 18, 17.

33. NSW Health Department procedures for organ donation after brain death are very poorly drafted. But they appear to *require* the consent of relatives before removal can occur.³⁷ If this is the case, then the procedures *unlawfully* restrict the discretion, vested in the designated officers by Parliament, to authorise removal of a consenting donor's organs.³⁸
34. It may be the case that it is necessary for a designated officer to take the views of relatives and the Department into consideration when making a decision exercising their discretion under the Act. But legally the discretion is granted by statute to the designated officer, not to relatives or departmental policy makers. In all likelihood, it is an improper exercise of a designated officer's discretion to follow blindly departmental procedures that require the consent of a deceased donor's relatives – if that is indeed what departmental procedures require.

³⁷ NSW Health Department, *Use and retention of human tissue including organ donation, post-mortem examination and coronial matters* (8 January 2004) Circular 2004/1, [5.7(f)] & [5.7(h)]. Available at: <<http://www.health.nsw.gov.au/fcsd/rmc/cib/circulars/2004/cir2004-1.pdf>>.

³⁸ it is a basic principle of judicial review of administrative action that policy may not fetter a discretion, nor should it be followed if it is inconsistent with the Act: see Douglas, n 19, 'Chapter 12: the exercise of discretionary power', 489 ff.

2.4 balancing the rights of the living and the dead

35. In 1977, the Australian Law Reform Commission recommended that the wishes of a donor should be paramount.³⁹

A competent adult should have the right to give his body or any part of it for the purpose of transplantation or other therapy or for medical or scientific purposes. His wishes should be paramount. No person (except the Coroner in a case falling within his jurisdiction) should have power to overrule the decision.

36. The ALRC also made the following observations with respect to a donor's relatives:⁴⁰

Wishes of relatives: Some people have strong, sincere, opinions that the wishes of close relatives should not only be considered but even regarded as crucial, before tissue may be removed from a dead person. ...[However, others] regard as paramount the deliberate wish of a person to give his body or part of it. The Commission endorses this support for the principle of personal autonomy and considers that it is the preferable approach. In addition there is a clear public benefit attaching to donation which should not be frustrated by relatives or others.

37. The NSW Health Department's recent discussion paper highlights the pitfalls in amending the *Human Tissue Act* to make the wishes of the donor paramount (footnotes omitted):⁴¹

There would be undoubted consequences of such an amendment. It would put immense pressure on clinicians and designated officers who work with bereaved families. It would have the potential to cause significant distress to family members and to cause harm to family relationships. There are sections of the community whose religious beliefs require or value the burial or disposal of the body as a whole. Imposing donation on bereaved relatives who hold such beliefs, even where the deceased member of the family did not share those beliefs and expressed a wish for donation may, in some circumstances, be extremely damaging. Furthermore, the process of tissue donation is one which requires a designated officer to engage in the making of an intensely personal decision, the consequences of which will vary greatly from family to family. Any restrictions upon a designated officer's discretion may therefore be undesirable.

³⁹ ALRC, *Human Tissue Transplants*, n 1, [144].

⁴⁰ ALRC, *Human Tissue Transplants*, n 1, [140] (footnotes omitted).

⁴¹ NSW Health, *Organ and Tissue Donation and Use and Post Mortem Examination*, n 18, 17-18.

38. However, the fact that a close relative has a religious or other strongly-held objection to organ removal is *irrelevant* – because the deceased person, by giving consent, obviously did not share that religious or strongly-held conviction. It is a fundamental value of a free society that everyone has the right to decide what happens to their own body – both in life and in death. This value lies at the heart of many of CCL's policies, including respect for the right of all women to choose to have an abortion. The choice of a living person to donate their organs and tissue, in the event of their death, should be afforded the same inalienable respect. To quote the great liberal thinker, John Stuart Mill: 'Over himself, over his own body and mind, the individual is sovereign'.⁴²
39. Furthermore, in our legal tradition there is no property in a corpse.⁴³ This means that relatives cannot claim to *own* the body of a deceased family member. In law, relatives only have *duties* towards the body relating to its burial.⁴⁴ Morally, relatives have no right to disrespect the lawful wishes of the deceased person in the context of how their body is to be dealt with.

⁴² John Stuart Mill, *On Liberty* (1859), Chapter 1 'Introductory'.

⁴³ *Doodeward v Spence* (1908) 6 CLR 406. See also: [Smith v Tamworth City Council](#) (1997) 41 NSWLR 680.

⁴⁴ *Doodeward v Spence* (1908) 6 CLR 406, 411: '...when a human being dies property in his body does not vest in anyone, although certain persons have duties, and perhaps rights, with respect to it'.

2.5 importance of informing family of your consent

40. As well as giving written consent to organ donation, it is important for a donor to talk to relatives about their decision. According to the Organ Donation Network:⁴⁵

Q. Can my family stop me from donating?

Experience shows that a family does not usually go against the known wishes of a family member after death. Problems may occur when the families do not know their wishes, which is why it is important to talk to your family. It is currently the procedure in Australia to gain a signed medical authority after death from the senior next of kin before any organ donation occurs.

41. According to Australians Donate:⁴⁶

Even though you may have joined the Australian Organ Donor Register or ticked 'yes' on your driver's licence, your family will be asked to confirm your decision regarding donation of your organs and tissues for transplantation. Experience shows that where a family knows their relative's intentions, it is most unusual for them not to support their decision. Knowing your wishes (whether yes or no to donation) can help to ease your family's stress at a difficult time.

42. Such a simple step as informing your relatives of your decision to donate organs might go a long way towards ensuring that your wishes are understood and respected after your death.

⁴⁵ Organ Donation Network, *Frequently Asked Questions*, <<http://www.organ.redcross.org.au/>>.

⁴⁶ Australians Donate, *Frequently Asked Questions*, <http://www.organdonation.org.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//05_FAQ>.

3. conclusion

43. The clearly identified issues at stake in this context are:
- (i) the wishes of the deceased
 - (ii) the wishes of the deceased's senior next-of-kin
 - (iii) the public interest in the donation of useable organs
44. The law grants hospital staff a discretionary power to follow the written consent of a deceased person by removing their organs for donation. Hospital staff are legally obliged to consult with the deceased's next-of-kin to determine whether the deceased person had revoked their consent.
45. The law does not grant a veto power to a deceased person's relatives over the deceased's (unwithdrawn) written consent to the removal of his or her organs or tissue.
46. Anecdotal evidence suggests that, in the vast majority of cases, relatives abide by the wishes of the deceased family member to donate their organs.⁴⁷ In those cases where relatives object to removal, despite the deceased's written consent, hospital staff are placed in a very difficult position. Family members might genuinely suffer psychologically if their objections are not adhered to.
47. However, there is a genuine public interest in seeing the deceased person's wishes carried out. There are people whose lives depend on the donation of human organs and tissues.
48. The 'ethical' approach, adopted in Australia, effectively grants family members a veto over the wishes of a deceased person to donate their organs. This approach seeks to balance the interests of the deceased with the interests of his or her living relatives. But this appears to be a far too narrow approach. The better ethical approach is to balance the interests of the living: the psychological harm to the deceased's relatives against the lives of those who need the organs to live or improve the quality of their lives. It is so rare an occurrence that a consenting donor dies in circumstances favourable to organ donation, that society at large has a right to expect that the wishes of the donor will be respected.
49. Only in the most extreme of circumstances should the interests of close relatives outweigh the combined interests of a consenting donor and a needy donee. In all other cases, relatives who wish to override their deceased loved one's consent should be offered grief counselling and other supports to help them through this difficult period, but they should *not* be granted a veto.

⁴⁷ NSW Health, *Organ and Tissue Donation and Use and Post Mortem Examination*, n 18, 18.

4. Appendix: further information

Organ Donation Network (NSW/ACT)

Telephone: (02) 9229 4003

Fax: (02) 9229 4413

Email: lifelink@arcbs.redcross.org.au

Mail: 153 Clarence St, Sydney NSW 2000

WWW: <http://www.organ.redcross.org.au/>

Australian Organ Donors Register

administered by the Health Insurance Commission

Telephone: 1800 777 203

WWW: http://www.hic.gov.au/yourhealth/our_services/aodr

registration forms also available at all Medicare offices

Australians Donate

Suite 2, Level 3

20-22 Albert Road

South Melbourne VIC 3205

Tel: (+ 61) 03 9696 0651

Fax: (+ 61) 03 9696 0681

Email: info@organdonation.org.au

WWW: <http://www.organdonation.org.au/>