Organ and Tissue Donation and Transplantation

2012

1. Preamble

1.1 The AMA supports organ and tissue donation and strongly encourages individuals to consider their views and discuss them with their family.

1.2 One organ and tissue donor can help more than 10 people by saving a life, improving the quality of life, and restoring body function. Organs that can be donated include the heart, lung, kidney, liver, pancreas, and eyes while tissues include heart valves, skin, bone marrow, and musculo-skeletal tissue.

1.3 Australia is a leader in organ and tissue transplantation and donation rates are improving. There are approximately 1600 people on the transplant waiting list. Waiting times vary between 6 months and 4 years; however, some on the list will die before an organ becomes available.¹

1.4 By increasing Australia’s rate of organ and tissue donation, more individuals, and their families, will benefit from receiving life-enhancing organs and tissues. This also means that our healthcare system benefits as transplantation of some organs and tissues, such as kidneys and corneas, is cost-effective compared to the expense of providing ongoing treatment for those waiting for a transplant.

1.5 The AMA believes that Australia’s donor rates can be increased through enhanced public education and awareness of organ and tissue donation as well as increased public confidence in Australia’s donation and transplantation system. Greater public awareness of the shortage of donor organs and tissues, the opportunities for donation, and the facts about organ and tissue donation should result in more people making the choice to become an organ and tissue donor.

1.6 The AMA considers enhancing public trust and confidence in the organ and tissue donation and transplantation system will increase donation rates. The AMA believes that organ and tissue donation and transplantation should be based on the following ethical principles:²

- Donation is altruistic, for the benefit of others;
- The choice to donate is informed and voluntary;
- The choice to donate (or not) is respected. This includes a right to change a donation choice;
- The family’s consent to donate (or not) their relative’s organs or tissues is respected;
- Donor families are treated with respect, compassion, and dignity;

The needs of the donor and their family take precedence over organ procurement;
Organs and tissues are allocated fairly;
The recipient consents to transplantation;
The privacy and confidentiality of donors and recipients should be respected;
The primary obligation of doctors is to their patients, whether they are potential donors or recipients. It can be seen as a conflict of interest for the same medical team to look after both the donor and the recipient. There should be a separation of roles between the medical team involved in caring for the donor and their family, the medical team involved in retrieving the organs and tissues, and the medical team involved in caring for the recipient;
The system for undertaking organ and tissue donation and transplantation is safe, accountable, transparent, and has the capacity to meet the current and future demands for, and availability of, organs and tissues.

1.7 A nationally-coordinated approach to organ and tissue donation is essential to increase donation and transplantation rates. In 2009, Australia’s Organ and Tissue Authority (the Authority) was established under the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (the Act). The purpose of the Authority is to develop a nationally coordinated approach to organ and tissue donation for transplantation in liaison with States and Territories, consumers, clinicians, and the community.

2. Determination of Death

2.1 Organs and tissues may be donated by deceased donors or living donors. As defined by the National Health and Medical Research Council (NH&MRC), organ donation after death can only occur when the potential donor dies in hospital under certain circumstances.²

2.2 Donation after death may be possible where the individual’s brain function is irreversibly lost but ventilation is still maintained by a machine – this is referred to as donation after loss of all brain function (or ‘donation after brain death’). Donation after death may also be possible when it has been agreed by all parties that ongoing treatment is no longer in that individual’s best interests and will die shortly after withdrawal of life-sustaining treatments – this is referred to as donation after loss of circulation (or ‘donation after cardiac death’).²

2.3 Most tissues do not require a constant supply of blood to be suitable for transplantation; therefore, donated tissue may be stored for varying periods of time before being transplanted.²

3. Free, informed donor choice

3.1 In Australia, as well as overseas, there continues to be debate regarding the benefits of ‘opt in’ vs ‘opt out’ consent systems for rates of organ donation.³⁴⁵⁶⁷ The current ‘opt in’

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system requires the explicit consent of the individual, or where the individual’s donor wishes are not known, the explicit consent of a legally-recognised surrogate, before donation can proceed. In an ‘opt out’ system, also known as presumed consent, individuals are considered to consent to organ donation unless they have expressed an objection to donate.

3.2 Either system of organ and tissue donation should be based on free, informed donor choice, involving the right to choose, as well as to refuse, to be an organ and tissue donor. A ‘free’ choice is one that is free from undue influence or coercion. An informed choice requires the individual to be fully informed, and to clearly understand and appreciate the following:

- the clinical aspects of organ and tissue donation;
- the current system and process for consenting to, or refusing to, be an organ and tissue donor. The consent, or refusal, process should be easily understood and readily accessible to everyone;
- any other information relevant to the individual to make an informed choice;
- interpreter services will be required in some cultural settings.

3.3 An individual may consider donation of their organs and tissues after death (a deceased donor) or may consider donating organs and tissues while still alive (a living donor).

4. Public education and awareness

4.1. Public education and awareness of organ and tissue donation is an essential aspect of increasing rates of donation. Relevant campaigns raise awareness of the shortage of donor organs and tissues, provide information on the opportunities for donation, and facilitate informed donor choice.

5. Facilitating an informed donor choice

5.1 An informed choice requires information that is accurate, balanced, comprehensive, and understandable. An informed choice should be free from undue influence or coercion.

5.2 Individuals may discuss organ and tissue donation and transplantation with their General Practitioner, who can respond to questions and address concerns.

5.3 Individuals have the right to change their donor choice at any time. It’s important, however, to make family members aware of this and to change the choice on the register (for those who registered their initial choice).

6. Making that choice known to others

6.1 Once an individual has made the choice regarding organ and tissue donation, that choice should be made known to others.

6.2 Individuals should register their choice regarding organ and tissue donation on the Australian Organ Donor Register. The Register records an individual’s decision to become a donor (or not) and which organs and tissues they agree to donate. The Register can be accessed by authorised medical personnel anywhere in Australia, 24 hours a day.

6.3 Individuals should make their choice regarding organ and tissue donation known to their family members. Even if an individual has registered as an organ and tissue donor, their family will be asked to confirm the wishes and give their consent. If an individual is not registered, the family will be asked to give their consent to donation.

6.4 Family members should never be pressured or coerced into consenting to organ or tissue donation.

6.5 The AMA strongly encourages families to support the donor wishes of their relative.

7. Donor families

7.1 Donor families make an important contribution under difficult circumstances. They should be treated with respect and compassion and receive appropriate support and counselling before and after donation.

7.2 Donor families should not incur any financial costs in relation to donating a relative’s organs or tissues.

8. Living donors

8.1 There are unique ethical considerations relevant to living donors, where the donor undertakes a risk of harm for the benefit of the recipient.

8.2 Living donation can include regenerative tissue such as bone marrow or whole organs (such as kidneys) or parts of organs (such as livers). The level of risk to the donor is dependent on whether donation involves tissues or an organ. Donating regenerative tissue involves a lower risk to the individual than donating an (non-regenerative) organ.

8.3 Living organ donors undertake a physical risk associated with undergoing surgery. They also risk their future health should a problem arise in relation to living with one organ (or part of an organ).

8.4 Living donors may also experience adverse psychological impacts from donation; for example, if the transplantation is unsuccessful, if the donor becomes sick in the future, or if the relationship with the recipient (where known) becomes difficult.

8.5 The AMA supports the following ethical principles specific to living donation:9

- Living donation must be altruistic;

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• Living donation should take place only where there are clinically acceptable risks of short and long-term harm to the donor and a high likelihood of success for the recipient;
• Living donors must consent to donation. The decision to donate must be free and informed;
• The living donor has the right to change their mind to donation;
• The autonomy and welfare of the living donor should take precedence over the needs of the recipient to receive an organ or tissue;
• There should be independent and separate assessment, advice, and advocacy for the living donor.

8.6 Living donation becomes particularly challenging when it involves a potential donor who lacks decision-making capacity (e.g., a child). Living donation from an individual who lacks decision-making capacity should only be considered in exceptional circumstances, where:

• The risk to the donor is clinically acceptable and the tissue is regenerative;
• There is an expected benefit to the recipient;
• Donation is a last resort and there is no other donor available;
• Donation is to a close relative;
• The parents or guardian consents to donation. Efforts are made to ensure the potential donor understands and appreciates the significance of donation, as much as possible, relevant to their decision-making capacity;
• An independent judgement considers the donation is not contrary to the donor’s overall best interests (e.g., where a child donor may save the life of their parent or sibling);
• Any additional required legal authorisation is obtained, where relevant (e.g., court or tribunal).

8.7 Reimbursement for expenses associated with living donation such as medical care, travel, accommodation, meals, and lost wages is appropriate.

9. Allocation of organs and tissues

9.1 There is a need to consider both equity and utility when determining eligibility to receive organs and tissues. The allocation of available organs for transplantation must be fair, equitable, accountable and transparent, from placement on the waiting list to allocation of organs amongst those on the list, based on clear clinical and ethical criteria.

9.2 There should be no discrimination based on social status, lifestyle, or behaviour. However, it is acknowledged some behaviour and lifestyle choices may be associated with disease processes that reduce the likelihood of successful transplantation. It is appropriate to take the following factors into account:

• Relative urgency of need;
• Medical factors which affect likelihood of success (e.g., tissue matching);
• Relative severity of illness and disability;
• Relative length of time on the waiting list;

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10 The Transplantation Society of Australia and New Zealand. Organ Transplantation from Deceased Donors: Consensus Statement on Eligibility Criteria and Allocation Protocols 23 June 2011 Vs 1.1
• Likelihood that the recipient will (be able to) comply with the necessary ongoing treatment after transplantation.

10. Consent to transplantation

10.1 Potential recipients must consent to receiving a transplant. Where a potential recipient refuses a particular transplant, this should not jeopardise their position on the waiting list (eg., if a recipient refuses a transplant from a living donor).

11. Trafficking of organs and tissues

11.1 The AMA supports a system for organ donation and transplantation that is voluntary and altruistic. Access to organs and tissues should be fair and just.

11.2 Financial incentives and other inducements to donate organs will compromise the voluntariness of the choice and the altruistic basis for organ donation. Payment for organs or tissues has the potential to take advantage of individuals who are economically-disadvantaged or otherwise vulnerable and may lead to organ trafficking.

12. Support for health professionals involved in organ donation and transplantation

12.1 Medical staff involved in organ and tissue donation and transplantation should have:
  • access to appropriate training and supervision. This includes General Practitioners who are encouraged to discuss organ and tissue donation with their patients as well as those directly involved in donation and transplantation;
  • access to counselling and support services.

12.2 A medical practitioner may have a conscientious objection to organ and tissue donation or transplantation; however, an objection should never put the donor or recipient at risk of harm nor should it undermine the role of organ donation and transplantation.

13. Workforce and infrastructure

13.1 The system for organ and tissue donation should be ethical, comprehensive, coordinated, and sustained. There should be adequate resources, both in terms of a suitably qualified and trained workforce as well as infrastructure, to support the current and future demands for, and availability of, organs and tissues.

14. Quality and safety

14.1 The system for organ and tissue donation and transplantation should be high-quality, safe, efficacious, and fair, based on transparency and accountability.\(^\text{11}\)

14.2 Whilst it is essential to maintain the privacy of individual donors and recipients, public access to information on the funding, organisation, execution, and (short-term and long-term)

outcomes of donation and transplantation activities is important to maintain public confidence and ensure the system remains high-quality, safe, efficacious, and fair.

14.3 The system for organ and tissue donation and transplantation should ensure:
- the privacy and confidentiality of donors and recipients;
- long-term follow-up of (living) donors and recipients, as required;
- data collection, evaluation, and monitoring of the short-term and long-term outcomes of (living) donors and recipients;
- the capacity to detect and investigate relevant adverse events or reactions.

15. Cultural sensitivities

15.1 For some individuals, their perception, values, and attitude towards death, as well as organ and tissue donation and transplantation, are influenced by a particular religious, spiritual, or cultural belief or value. A culturally-sensitive approach that respects the rights, beliefs, perceptions and cultural heritage of individuals is essential when discussing organ and tissue donation or transplantation with individuals and/or their family members.

15.2 Trained interpreters, along with culturally and linguistically appropriate material, may be required when providing information to people from culturally and linguistically diverse backgrounds.

15.3 Aboriginal Health Workers or Aboriginal Hospital Liaison Officers may be involved when communicating with Aboriginal and Torres Strait Islander peoples.