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Department of Health  
and Aged Care

# ***Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023***

Submission from the Department of Health and Aged Care  
to the Community Affairs Legislation Committee

27 June 2023



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**Department of Health  
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## Introduction

The Department of Health and Aged Care (department) welcomes the opportunity to make a submission to the Community Affairs Legislation Committee regarding the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023.

The *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (OTA Act) is the enabling legislation for the Organ and Tissue Authority (OTA). The department has policy responsibility for organ and tissue donation and transplantation and led the drafting of this Bill.

Making the decision to donate a loved ones' organs and tissues following their death, has a profound impact on the lives of many Australians. The Department gratefully acknowledges the generosity of donor families saying yes to donation, without whom organ and tissue donation and transplantation would not be possible.

## Background

The OTA is a statutory authority responsible for delivering a nationally coordinated approach to organ and tissue donation and transplantation, in partnership with the states and territories (through DonateLife agencies), clinicians, consumers and the community.

The OTA and DonateLife agencies conduct community awareness and educational activities to increase awareness of organ and tissue donation issues and to encourage people to register their donation decision, as well as to commemorate donors and recognise donor families. These often include the publication and dissemination of identifiable information about donors, with the consent of the donor/recipient's family or next of kin.

Each jurisdiction has its own Human Tissue Act (HTA), and these have varying limitations around the disclosure of information that may identify an organ and/or tissue donor and/or transplant recipient. While these provisions all have the same intent, which is to protect confidentiality for those who donated and those who receive transplants, there are differences about who is prohibited from disclosing information.

HTAs in all jurisdictions preclude people and professionals involved in the donation process from disclosing information about an organ and/or tissue donor. The provisions in Northern Territory, South Australia and Western Australia go further by prohibiting all persons from disclosing information, including the family members of donors.

The OTA Act also currently contains restrictive provisions regarding the type of people who can consent to the sharing of information about deceased donors. Under section 58 of the OTA Act, consent for the sharing of information can only be provided by partners of the deceased donor or by parental guardians if the donor was less than 18 years old. This restricts opportunities for some donor families to consent to participate in public education and commemorative activities of the OTA and DonateLife.



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As a result, the OTA and Commonwealth-funded (via the OTA) state and territory DonateLife agencies are limited in the ways they can deliver the national organ and tissue donation and transplantation program, and in particular, community awareness activities and events involving donor families.

### **Amendments to the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008***

The Bill seeks to broaden the disclosure of information provisions in the OTA Act to allow DonateLife agencies, grant recipients and ‘authorised family members’ to publish, disseminate or disclose information about deceased donors/recipients for the purposes of the OTA’s community awareness, promotional, educational or commemorative activities, without breaching law of a state or territory.

The legislation operates to enable disclosures of information where they are currently prohibited. It does not create any new restrictions on disclosures. It also does not prohibit any disclosures where they are already authorised by state and territory HTAs.

The Bill will allow the OTA and DonateLife agencies to obtain consent from an extended list of family members of a deceased donor before including information about the deceased donor in their promotional and educational activities. If consent has been given by an ‘authorised family member’ as defined in the Bill, a law of a State or Territory does not prevent the publication or dissemination by the OTA and DonateLife agencies.

The Bill allows for the publication, dissemination or disclosure of information by DonateLife agencies or grant recipients for the purposes of an educational, promotional, community awareness, or commemorative activity that is relevant to an organ or tissue donation and transplantation matter. This provision does not allow for the publication, dissemination or disclosure of information for activities beyond the remit of OTA and DonateLife agencies and is not intended to facilitate direct contact between donor families and transplant recipients.

These proposed amendments align with the sentiment that many donor families support the idea of raising community awareness about donation and registration and commemorating their family member in remembrance services. The legislation does not prohibit donor families from raising community awareness and commemorating their family member through activities separate from those undertaken by the OTA and DonateLife agencies.

The community and educational activities undertaken by the OTA and DonateLife agencies are intended to support organ and tissue donation and transplantation by raising awareness and increasing the number of people who choose to register as organ and tissue donors. By enabling family members to consent to share information to support these activities, the Bill will contribute to efforts to save lives by increasing the number of organ and tissue donations. It will also give more family members the option to participate in activities that commemorate their loved one and recognise and value the difficult decision to consent to organ and tissue donation.

The department will work closely with the OTA in the implementation of the legislation.



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## Consultation on Bill

This Bill was drafted following advice from the Australian Government Solicitor (AGS). Drafting instructions were provided by the department to the Office of Parliamentary Counsel (OPC). The Bill draws on definitions from the Family Law Act, and includes an expanded list of individuals to be approached for providing consent for the disclosure of information, to recognise the complexity of family relationships and promote inclusion. The amendments provide that an authorised family member includes a partner, a parent or legal guardian, a child, a sibling, a grandparent, a grandchild or those with kinship ties where relevant.

The OTA, the Department of the Prime Minister and Cabinet (PM&C), and the Attorney General's Department (AGD) have been consulted on the proposed legislative amendments. AGD advised the Department regarding human rights, and equality and non-discrimination implications within the Bill. The Bill is compatible with human rights because it promotes the protection of human rights, and where it may limit human rights, those limitations are reasonable, necessary and proportionate.

All state and territory health ministers have been consulted on the Bill and have been given the opportunity to comment on the Bill prior to its finalisation, and all support passage of the Bill. Targeted First Nations Health organisations including the National Aboriginal Community Controlled Health Organisation, the Australian Indigenous Doctors' Association, and the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM), have also been consulted.

The CATSINaM advised the Department that the definition of "authorised family member" is sound, and that while not all First Nations peoples have active kinship systems, the wording allows for only those with kinships systems to benefit from the definition.

## Considerations

### Stakeholder feedback

While most stakeholders consulted have been supportive of the intent of the Bill, the Department is aware of concerns raised by one stakeholder that the passage of this Bill will restrict families' ability to communicate about their loved one, and give the OTA control of their loved one's information. The Department appreciates that communication about deceased donors and deceased recipients is a matter of particular concern for those families who have lost a loved one and wish to ensure that they can tell their story. However, these concerns are based on an inaccurate interpretation of the Bill.

To clarify the operation of the Bill in relation to these concerns:

- No provision in this Bill affects the ownership of information relating to deceased donors and recipients.
- There is no assumption that when a family has consented to organ donation they have also consented to the use of their loved one's information for the purposes of community awareness, promotional, educational or commemorative activities. This requires a separate and specific consent process by an authorised family member.



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- This Bill does not propose any restrictions on how family members conduct community awareness, promotional, educational or commemorative activities or engage in any other communications about their loved one.
  - Where a family chooses to consent to the OTA or a DonateLife agency using information about their loved one for community awareness, educational, promotional or commemorative activities, that family will continue to be able to engage in other communications about their loved one. Where those communications align with the purposes of the OTA Act, it will operate to remove any risk of those activities being inconsistent with relevant state and territory laws.
  - Where a family does not consent to the OTA or a DonateLife agency using information about their loved one for community awareness, educational, promotional or commemorative activity, that family will continue to be able to engage in other communications about their loved one, and those activities are not affected by any provisions of this Bill.

### **Contact between donors and recipients**

The intent behind the amendments in the Bill is to allow authorised family members to give consent to the disclosure of information about a deceased donor or recipient. They will not facilitate direct contact between donor families and recipients. Governments intend to protect the right of both donor families and transplant recipients who wish to remain anonymous.

There are ways that donor families and recipients can communicate with each other. This is done anonymously, as Australia's organ and tissue donation program is confidential. Legislation and policy in each state or territory prevent health professionals from disclosing information that might publicly identify a donor or transplant recipient. Donor families and those who have received a transplant can contact each other anonymously through their jurisdictional DonateLife agency.

The Commonwealth in collaboration with the Organ and Tissue Authority and all state and territory governments, has released an All-Governments statement about the proposed amendments, which affirms the current policy in Australia - contact between donor families and those receiving an organ transplant is anonymous. Confidentiality and protection of the identity of those who donate organs and tissues is paramount. DonateLife agencies will continue to facilitate anonymously written contact for donor families and those who have received a transplant should they request this.

The All-Governments statement is available on the OTA website at:

<https://www.donatelife.gov.au/sites/default/files/2023-06/Health%20Letterhead%20-%20All%20Governments%20Statement.pdf>

### **Human Tissue Act harmonisation**

Each Australian jurisdiction regulates human organ and tissue donation and transplantation through its own Human Tissue legislation. These laws also include other human organ and tissue related matters such as blood donations, the definition of death, post-mortem examinations, and trade, advertising to procure and research involving human tissue and organs.



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It has been almost fifty years since all Australian jurisdictions introduced legislation regulating the use of human tissue. HTAs were introduced in response to the recommendations from the Australian Law Reform Commission (ALRC) in the Human Tissue Transplantation report of 1977. The ALRC's recommendations were to provide uniformity across the jurisdictions regarding the donation of blood, tissues and organs for transplantation, and for scientific, therapeutic and medical purposes.

Jurisdictions varied in their adoption of the recommendations and have since amended legislation independently of each other in response to medical and scientific developments, and specific local issues. This has created inconsistencies in interpretation and administrative arrangements, including definitions of death clauses, consent to donation, post-mortem arrangements, as well as the disclosure of information.

The need to review and harmonise HTAs has been identified by all governments, with jurisdictions indicating support for a principles-based review to ensure modernisation and harmonisation across jurisdictional HTAs.

This Bill is an interim measure to immediately address the specific issue around the disclosure of information as they pertain to the OTA and DonateLife agencies. A broader review of HTAs is required to properly resolve the disclosure of information issue as well as the other identified inconsistencies. The Commonwealth will continue to engage with jurisdictions to progress this work.