



Australian Government
Organ and Tissue Authority

Community Affairs Legislation Committee Submission

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

Introduction

The Organ and Tissue Authority (OTA) 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 OTA.

The Department of Health and Aged Care has policy responsibility for organ and tissue donation and led the drafting of this Bill.

The OTA thanks all organ and tissue donors, who have transformed the lives of people needing a transplant through donation. We also acknowledge the dedication and commitment of donation specialist staff, transplantation teams, community advocates and supporters. Transplantation is only possible through the donation of organs and tissues, and its life-changing benefits would not be possible without this shared commitment.

The Organ and Tissue Authority and the national organ donation program

The Australian Government's Organ and Tissue Authority (the OTA), leads the national program to increase organ and tissue donation, so that more Australians can receive a life-changing transplant.

Globally there will never be enough organs available to meet the demand for those needing a transplant. Australia's program is aimed at optimising all donation and transplant opportunities so more people can access a life changing transplant.

The national program, announced by the Australian Government in 2008 and agreed by all governments, was implemented to improve practices related to deceased organ and tissue donation to achieve a significant and lasting increase in the number of life-changing transplants. The foundations of the reform were drawn from successful practices in world-leading donation and transplantation countries and adapted to the Australian environment. The program is delivered in collaboration with all governments, the DonateLife network, the clinical sector and the community.

Building public support for donation

A key to the success of the national program is delivery of an integrated communications and engagement program to build public support for donation. Meaningful, consistent and effective communication with the Australian public is essential to building awareness and acceptance of organ and tissue donation.

The OTA is responsible for national public awareness and education activities as well as supporting local community awareness activities to normalise conversations about organ and tissue donation in Australia. The OTA and state and territory based DonateLife agencies conduct awareness and educational activities to increase awareness of organ and tissue



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donation and to encourage people to talk about donation and register to be a donor, as well as to commemorate donors and their families who said yes to donation. 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.

A key goal in the OTA's 2022-2027 Strategy is to build support for donation and to encourage more people to say yes to donation.

Specifically, our objectives are to:

- *Raise awareness* of the need for organ and tissue donation and the benefits it gives to another person needing a transplant. Access to life-changing and often life-saving transplantation depends on the willingness of people to donate and public awareness and confidence in the donation process.
- *Increase family discussion* about organ and tissue donation. In Australia, families are always asked to agree to donation. It is important registered donors have discussed their donation wishes with their family.
- *Increase registration* on the Australian Organ Donor Registration (AODR). Around 4 in 5 Australians aged 16 years and over support organ and tissue donation but only 1 in 3 have registered to be a donor. Being a registered donor has a direct impact on families agreeing to donation.

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

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 health 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 contains restrictive provisions regarding the type of people who can consent to the sharing of information about deceased donors in the OTA's communications and engagement program. 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.

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 program, and in particular, public awareness activities and events involving donor families.

The proposed Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 (the Bill) will address the current limitations for the OTA, and DonateLife agencies in the way in which delivery of public awareness, educational activities, and commemorative events for donors and their families can take place.



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The amendments allow the OTA, DonateLife agency staff and authorised family members to publish, disseminate or disclose information about deceased donors/recipients for the purposes of the OTA's public awareness, promotional, educational or commemorative activities. Such activities are intended to encourage people to register on the AODR and have conversations with their family about donation.

The Bill will allow the OTA and DonateLife agencies to obtain consent for disclosure of information from an extended list of family members of a deceased donor. This will allow more families to consent to sharing information about their family member who became a donor in OTA's promotional and commemorative 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 amendments introduced through this Bill do not allow for the publication, dissemination or disclosure of information for activities beyond the OTA's national Community Engagement Program.

Importantly, the passage of this Bill does not prevent families from undertaking public awareness activities or commemorating their family member separate to those undertaken by the OTA and DonateLife agencies. This is irrespective of whether the family has or has not provided consent to the OTA or DonateLife agency to use information about their loved one for community awareness, educational, promotional or commemorative activities.

The amendments proposed through this Bill are not intended to facilitate direct contact between donor families and organ and tissue transplant recipients. The right of both donor families and transplant recipients to remain anonymous is paramount. Governments intend to protect the right of both donor families and transplant recipients who wish to remain anonymous.

Practical implications

As best practice, the OTA and/or DonateLife agencies do not actively solicit donor families or transplant recipients for the purpose of sharing their stories. The majority of the stories about deceased donors or transplant recipients, published as part of the OTA's public awareness and education activities, are collected in the following ways:

- Individuals contact the OTA directly, through the website or on social media channels. Once a story is received it is verified and any identifying content is removed (including specific dates and last names) before it is shared publicly. <https://www.donatelife.gov.au/all-about-donation/donation-stories>
- Individuals reach out directly to the DonateLife agency in their state/territory or express a desire to share their stories when they are interacting with a Donor Family Support Coordinator or Donor Specialist Nursing Coordinator.

In either scenario, any information shared publicly by the OTA or DonateLife agencies is done so with the consent of all parties involved. However, depending on the state or territory in which the information is published there are differences about who can consent to the sharing of this information, thereby limiting the opportunity for this information to be shared publicly without breaching state and territory laws.

This Bill seeks to set a unified standard across Australia, when consent has been given by an authorised family member as defined in the Bill. The law of a state or territory will no longer prevent the publication or dissemination of the information. This will enable the OTA, DonateLife agencies and grant recipients to continue promotional and education activities



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involving donor families and share their stories no matter what state or territory they are sharing their stories in. This is a vital part of our national communications and engagement program to increase awareness of organ and tissue donation.

Donor families and transplant recipients play a critical role in the OTA's communications and engagement activities through sharing their experiences with organ and tissue donation and transplantation. For families, the ability to talk about their loved one being a donor can be an important part of the healing process and allows them to celebrate their loved one's life and the impact they have had on another's through the selfless act of donation to provide a lifesaving transplant opportunity.

Donor families who share their experiences about donation can also often be powerful advocates for organ donation and transplantation in the community. The opportunity to speak out about their personal experiences can often help to address and dispel the many myths about organ donation and to normalise the subject for the Australian community as part of end-of-life care and family discussion.

By enabling family members to consent to share information to support these activities, the Bill will contribute to efforts to save lives by increasing awareness about organ and tissue donation, with the aim of more people registering and talking to their family about donation. And, in turn, increase Australia's consent rate to donation in the hospital. This means more people saying yes to donation which will result in more people receiving a transplant. It will also give more family members from across Australia 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.

Each year the OTA, in partnership with DonateLife agencies and grant recipients across Australia, undertake a range of public awareness and educational activities dedicated to raising awareness of organ and tissue donation. In 2022, for example, these included:

- Eye and tissue awareness week (April): digital awareness activities about eye and tissue donation.
- DonateLife Week (July): the OTA's largest annual public awareness drive about organ and tissue donation. DonateLife Week accounts for around 30% of new registrations annually, attributed to heightened media coverage, marketing, PR, events, and community engagement activities.
- Thank You Day (November): a national day to reflect on the importance of organ and tissue donation, and acknowledge the generosity of donors and their families, simply by saying Thank You to those who became donors and helped save so many lives.
- Services of Remembrance (February through to November): commemorative services to remember those who became donors and recognise their families who said yes to donation.

In addition, the OTA produces a range of owned and earned educational and public awareness materials, including digital and content, through donatelife.gov.au and via social media - Facebook, Instagram, Twitter and LinkedIn.

Sharing the stories of those whose lives have been changed through organ and tissue donation is a powerful way to generate engagement and awareness. In 2022, DonateLife shared 4,269 news stories. They were seen a total of 589.44 million times. There was a total of 94,008 people who visited the donatelife.gov.au registration page online for the first time



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and there was a 43% increase in the number of times DonateLife content appeared in people's social media feeds.

Donation is only possible through the generosity of individuals and their families who say yes to donation, to save and transform the lives of others. The OTA continues to support donor families and understands the importance of being able to commemorate their loved one's donation.