



Donor Families Australia celebrating our 10th anniversary



Donor families angry after Reps silence their rights.

No public consultation for rushed changes to Donation laws scheduled for July Senate sitting.

If passed, the Legislation¹ will silence free speech for donor families across Australia to say their loved one was a donor.

- At important moments such as funeral's families will **be unable to say their relative was a donor and saved the lives of others.**
- Families will be denied the right to share their immense pride and gain comfort and solace at a time of heartbreak and tragic loss. **Stories of hope that help others donate.**
- This directly impacts DFA and the wide-ranging support that is provided to Australia's donor families and **positive work of educating, role modelling donation and garnering support for organ and tissue donation in Australia.**

If passed, this legislation will harm donation by reducing community trust and consent.

- The Australian **public would be understandably distressed** to know that bereaved people across Australia were disrespected and silenced in this way.
- In signing the **Australian Organ Donor Registration** form, we are certain many would be shocked to know their donation consent would **waive family members rights** to talk about their donation following death.
- DFA **seeks an inquiry into the way** the legislative change has been developed.
- DFA **demand appropriate widespread community consultation** with Donor Families and others impacted by existing legislation relating to organ and tissue donation to bring them in-line with the 21st Century and expectations of transparency, freedom of speech and association and humanity.

"Donor families want to own and control their loved one's information." Bruce McDowell, Chair of Donor Families Australia.

Felicity McNeill PSM, former **CEO of the Australian Organ and Tissue and Transplantation Authority**, and Chair of Better Access Australia, support DFA's position stating,

"We call for the Government and the Senate to:

- 1. Delay passage of the Bill until full consultation has been undertaken with the donor family community; and***
- 2. Ensure a truly national approach to addressing the private information disclosure issues within this Bill by linking its passage to similar changes in all state and territory human tissue laws to protect the rights of donor families and recipients by 30 June 2024."***

Families of Organ and Tissue Donors are angry the legislation 'slipped' through the lower house without public consultation.

- This legislation **harms bereaved families' freedoms of speech and association.**
- **This legislation specifically impacts families of organ and tissue donors and deceased recipients.**

¹ Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 (Cth)

https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22legislation%2Fbills%2F7030_first-reps%2F0000%22;rec=0

- If passed it will **override all states and territories** related legislation.
- **The legislation is designed to protect only OTA**, DonateLife agency staff and ‘authorised’ donor family members.
- This legislation is paternalistic and archaic. It does not respect people who gave consent to donation or supported another’s wish to donate.

Simply put:

This legislation is a direct response to legal advice DFA received in July 2021. DFA brought this advice to the attention of the Commonwealth and OTA. DFA deeply regret that to date, we have been actively excluded, omitted, or silenced from consultation and engagement by the OTA and Commonwealth regarding this and other matters pertaining to organ and tissue donation practice. Since learning the proposed 2023 amendment was under review, **DFA sought further legal advice that confirmed the legislation would provide more power to the OTA and its agencies and continue to silence and threaten bereaved families of donors and deceased recipients.**

The legislation silences donor families unless authorized by the OTA and agencies. If specifically authorized by the OTA family members are permitted to speak and tell their stories for four activities sanctioned by the Government’s Organ and Tissue Authority and the state-based DonateLife agencies:

- educational, commemorative, promotional or community activities that are relevant to an organ or tissue donation and transplantation.

The explanatory memorandum² accompanying the Bill states *“This provision does not allow for the publication, dissemination or disclosure of information for activities beyond the remit of OTA and DonateLife.”*

At best, this legislation is confusing and does not meet community expectations or standards. At worse, this legislation will cause lasting harms to the donor family community, who have already given so much expecting nothing but compassion and respect in return. It may also cause lasting harms to organ and tissue donation.

Further information about the ongoing Senate Inquiry including heartfelt submissions from individual donor families can be found at

https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/DisclosureofInformation/Submissions

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BOILERPLATE: Donor Families Australia is a national member-based independent support and advocacy group comprising families who have donated their loved ones’ organs and tissue. It's the only organisation of its kind in Australia specifically dedicated to Donor Families

² Explanatory memorandum

https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22legislation%2Fems%2Fr7030ems_f6d071ca-ec2b-423a-a84f-736db16b1436%22