

# **PARLIAMENTARY INQUIRY QUESTION ON NOTICE**

## **Department of Health and Aged Care**

### **Senate Community Affairs Legislation Committee**

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

**PDR Number:** IQ23-000056

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

#### **Written**

**Senator:** Marielle Smith

#### **Question:**

1. The Department's submission specifies that, where a family does not consent to a loved one's information being used by the OTA or a DonateLife agency for the four activities, the family will continue to be able to engage in 'other communications' about their loved one.
  - a. Can you outline what 'other communications' might entail, and how it would differ from community awareness, educational, promotional or commemorative activities?
  - b. Where family members do not consent to a loved one's information being used by the OTA or a DonateLife agency, are family members and other individuals able to conduct community awareness, promotional, educational or commemorative activities?
2. The Department's submission also states that the bill 'does not allow for the publication, dissemination or disclosure of information for activities beyond the remit of OTA and DonateLife agencies'. Can the Department clarify whether the bill would prohibit other organisations (i.e. non-OTA and non-DonateLife agencies) from disclosing information for the four activities related to donation and transplantation matters?
3. Submissions to the inquiry have made the following assertions:
  - The bill is trying to 'stop' donor families from contacting recipients, for example, by making it illegal to make non-anonymous contact through social media groups.
  - The bill 'makes it illegal in all states and territories for the donor family to talk (or post on social media etc) the name of their loved one, or any other information about them.'
  - There is a 'prohibition' on donor families publicly acknowledging donations outside of a connection to OTA or DonateLife.Can the Department address if these claims are true, both currently and in the event the bill passes?

**Answer:**

Each Australian jurisdiction regulates human organ and tissue donation and transplantation through its own Human Tissue Acts (HTAs). Each HTA has 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, and some jurisdictions also apply restrictions on disclosure to all persons, which may include the family of donors.

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 only as it pertains to the OTA and DonateLife agencies or OTA grant recipients.

Responses to Senator Smith's specific questions are provided below:

- 1. The Department's submission specifies that, where a family does not consent to a loved one's information being used by the OTA or a DonateLife agency for the four activities, the family will continue to be able to engage in 'other communications' about their loved one.**
  - a. Can you outline what 'other communications' might entail, and how it would differ from community awareness, educational, promotional or commemorative activities?**

"Other communication" refers to communication activities that an individual might undertake in a personal capacity that does not involve the Organ and Tissue Authority (OTA).

The Bill operates only to enable disclosures of information where they are currently prohibited. It does not create any new restrictions on disclosures. Nor does it prohibit any disclosures.

Specifically, the Bill enables the publication, dissemination or disclosure of information by the OTA, DonateLife agencies or OTA 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, in instances where such disclosures are currently prohibited.

The Bill does not place any restrictions on families communicating about or commemorating a loved one who has become an organ donor. However, as noted above, some state and territory legislation may restrict some communications.

Where the relevant state or territory legislation allows for the disclosure of deceased donor or recipient information by family members, families are able to engage in any other communications about their family member at their discretion i.e. discussing with a friend or neighbour or undertaking organ donor advocacy as an individual.

- b. **Where family members do not consent to a loved one's information being used by the OTA or a DonateLife agency, are family members and other individuals able to conduct community awareness, promotional, educational or commemorative activities?**

Yes. The Bill does not prohibit or restrict these activities. Where the relevant state or territory legislation allows for the disclosure of deceased donor or recipient information, family members and other individuals (with the family's consent) may continue to conduct these activities.

- 2. The Department's submission also states that the bill 'does not allow for the publication, dissemination or disclosure of information for activities beyond the remit of OTA and DonateLife agencies'. Can the Department clarify whether the bill would prohibit other organisations (i.e. non-OTA and non-DonateLife agencies) from disclosing information for the four activities related to donation and transplantation matters?**

The Bill does not prohibit or restrict other organisations from disclosing information for the purposes of an educational, promotional, community awareness, or commemorative activity related to donation and transplantation matters.

- 3. Submissions to the inquiry have made the following assertions:**

- **The bill is trying to 'stop' donor families from contacting recipients, for example, by making it illegal to make non-anonymous contact through social media groups.**

Non-anonymous (i.e. direct) contact is prohibited under existing state and territory law. The Bill does not change this.

- **The bill 'makes it illegal in all states and territories for the donor family to talk (or post on social media etc) the name of their loved one, or any other information about them.'**

This practice is currently prohibited in some jurisdictions under existing state and territory law. The Bill does not change this.

The legislation only operates to enable disclosures for the OTA, DonateLife and OTA grant recipients where they are currently prohibited. It does not operate to prohibit disclosures by anyone. As noted above, disclosures may be restricted by state and territory legislation. This Bill does not place restrictions on family members where the relevant state or territory legislation permits such disclosures.

- **There is a 'prohibition' on donor families publicly acknowledging donations outside of a connection to OTA or DonateLife.**

As outlined above, each jurisdiction has varying limitations around the disclosure of information by donor families.

The legislation only operates to authorise disclosures where they are currently prohibited for the OTA, DonateLife staff or OTA grant recipients. If the relevant state/territory legislation allows such disclosures by a family member, this can continue.