



20 July 2023

Committee
Donor Families Australia
c/- Ms Philippa Delahoy
via email: Philippa.delahoy@gmail.com

Dear Philippa

SUPPORT FOR BETTER CONSULTATION WITH DONOR FAMILIES ON PROPOSED CHANGES TO ORGAN AND TISSUE DONATION INFORMATION DISCLOSURE

Better Access Australia is writing to support Donor Families Australia's call for better consultation and improved protections for families who share their organ and tissue donation experience with the community as part of the Parliament's consideration of the *Australian Organ and Tissue Donation and Transplantation Authority Amendment (Information Disclosure) Bill 2023*.

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.

Better Access Australia wishes to be transparent in declaring a potential or perceived conflict of interest in writing on this matter, as our Chair and co-founder is a former Chief Executive Officer of the Australian Organ and Tissue Donation and Transplantation Authority (OTA). However, we also consider this makes us well placed to understand the concerns of those in the community who may be directly impacted by this Bill.

Lack of consultation and advance warning causing distress for donor families

Better Access Australia fully supports the work of the OTA, the Donate Life agencies and most importantly the work of donor families and recipients to raise awareness of the importance of organ and tissue donation. However, we note with some concern that there has been a lack of consultation with the donor family communities which is causing unnecessary stress, fear, and disempowerment in those who have already suffered considerable trauma at the sudden loss of loved ones.

This Bill was introduced to the parliament on 1 June 2023. Many members of the house of representatives stood in support of the Bill, but as the Deputy Opposition Leader, the Hon Sussan Ley MP noted, that support was accompanied by "*concerns with the amount of time for consultation that has been undertaken prior to the introduction of this bill, particularly in regard to the definitions contained in the bill. Time again, we are concerned by this government's refusal to allow for appropriate levels of consultation on their legislation to follow proper process.*"

Feedback from the community that they were not consulted on the Bill is reinforced by the Department of Health and Aged Care's submission to the inquiry which notes that their consultation was limited to the Departments of the Prime Minister and Cabinet and Finance and with first nations communities.

The opportunity for organ donation tragically comes about because of the sudden and unexpected loss of life. Critical decisions are made by family members in the most traumatic of circumstances with deadlines for decision-making placed on them at a time of great stress. There is no excuse for re-inflicting a sense of disempowerment and loss on the community by failing to take them on the journey of design and implementation of these reforms.

Neither the Minister's speech nor the Explanatory Memorandum articulate why this Bill is being progressed so quickly through the Parliament, causing distress to some donor families. The community has questions, it is seeking reassurances and has a right to be heard and compassionately engaged with. We encourage the parliament, the Minister and her department to fulsomely engage with the donor family community before progressing this legislation through the Senate. Make these changes with the community not to them.

Empowering OTA and DL agencies, but families still risk legal challenge in telling their own stories
Better Access Australia notes that the objective of this Bill is to ensure that OTA and DL Agencies have the legal right to share the stories of donors and recipients as approved by an expanded definition of family members. We fully support the sharing of these important stories in the community and removing the artificial legal barriers to doing so in both the OTA Act 2008 and state and territory human tissue acts.

However, we appreciate that the way the legislation is currently drafted causes concern to donor families as it appears to link their right to sharing their stories without repercussions from state and territory laws to only those circumstances where it aligns to the work of the OTA and DL Agencies. This needs to be clarified to the satisfaction of the families potentially impacted.

We note that Minister McBride stated that *"...each state and territory has its own human tissues act, which have diverse limitations around the disclosure of information that may identify a donor or a recipient..[and] as a result.. the OTA, is limited in the ways it can deliver its programs... The bill will allow DonateLife agencies, grant recipients and authorised families to publish, disseminate or disclose information without breaking the law of any state or territory."*

However, what the Minister hasn't made clear is that the Bill appears to only afford this protection where the communication of information by a family is within the scope and basis of OTA and DL Agency communications and information sharing by families not in line with the work of OTA and DL Agencies may not be exempt from actions from stated based human tissue acts.

We appreciate the federal government can only legislate with respect to its own areas of legal responsibility. However, as a recognised federal, state and territory initiative it is unclear why the passage of this Bill is not linked to a national commitment to the reform of arcane human tissue acts in the jurisdictions, noting that this legislation would likely have been subject to interjurisdictional agreement at Ministerial level.

As residents of the ACT, families in our territory have the full legal protection of sharing the stories about their loved ones as they see fit. But not all states and territories are as progressive as the ACT (and now the federal government) with the NT, SA and WA having some of the most restrictive laws in the country.

We are aware that DFA has written to individual governments to seek confirmation that irrespective of this legislation they will continue to refrain from enforcing their own laws that preclude the sharing of donor information and have received two positive responses. However, we do not think a 'promise not to enforce' is the appropriate way to handle this issue when it is being raised and addressed at the federal level with jurisdictional support.

Therefore, we would ask that the passage of this Bill be accompanied by a commitment from the Federal Assistant Health Minister to work with the states and territories to amend their own human tissue acts to ensure donor families and recipients have the right to talk about their loved ones as they deem appropriate. We would not consider legislating to restrict the rights of families who have lost loved ones to cancer, suicide, or transport accidents to discuss and share their stories. Yet, when the issue is extended to organ and tissue donation a process often a direct result of these causes of death, we are threatening families with legal repercussions for talking about their lived experience. It is not right.

The Federal Government should be taking the opportunity to lead on this issue and encouraging all jurisdictions to reform, rather than just highlighting the risks to families at the state and territory level going forward.

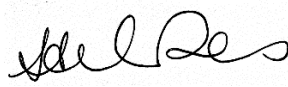
We thank DFA and all donor families for their brave and selfless work in raising awareness and support for organ and tissue donation in Australia. We cannot comprehend how hard reliving the sudden loss of your loved ones must be, and being forced to do so without forewarning, as has been the result of this process. However, we but hope that with the introduction of these new reforms further changes can be made by the Senate and then across Australia to ensure an end to the restrictions placed on loving families who want to talk about those that still matter so much to them.

If we can be of any assistance, please do not hesitate to contact Felicity directly at fmcneill@betteraccessaustralia.org.au.

Yours faithfully,



Felicity McNeill PSM
Board Chair



Helen Innes
Board Member



David Mackay
Board Member

Better health, disability and social services
Better Access Australia