

3 July 2023

Committee Secretary
Senate Standing Committee on Community Affairs
Department of the Senate
PO Box 6100
Parliament House
CANBERRA ACT 2600
AUSTRALIA

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

Dear Committee Secretary,

1. I am a proud donor family member and have major concerns about the proposed amendments to the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023.
2. I am also the Secretary of Donor Families Australia Inc. and I have provided a detailed description of my donation consent journey as well as co-authoring the submission to the Senate Inquiry from Donor Families Australia Inc.
3. My husband, Scott, became an organ and tissue donor on 21st January 2011; a remarkable legacy that tells you everything you need to know about this beautiful, generous, optimistic, community-minded Australian.
4. If the amendment to the Bill continues in its current form, it will be prohibited for donor families like mine to disclose this information to you¹.
5. To quote Section 58A(3) explanatory notes (with sentence underlined for emphasis):

“Section 58A (3)

Publication, dissemination or disclosure by an authorised family member

This item stipulates that an authorised family member of a deceased organ or tissue donor or recipient may publish, disseminate or disclose information that is likely to enable the identification of the deceased donor or recipient if it is for the purposes of either the OTA’s or a DonateLife Agency’s educational, commemorative, promotional or community activities that are relevant to an organ or tissue donation and transplantation matter. The publication, dissemination or disclosure by the authorised family members must be made:

(i) using a service to which paragraph 51(v) of the 23 Constitution applies;

(ii) using an electronic service (within the meaning of the 25 Online Safety Act 2021);

¹ In my situation, I have shared Scott’s story through OTA and DonateLife activities and as such I would not personally be in violation, as I believe that this would be considered a secondary publication.

(iii) in a Territory;

(iv) in a Commonwealth place (within the meaning of the 28 Commonwealth Places (Application of Laws) Act 1970);

(v) by a constitutional corporation.

This provision does not allow for the publication, dissemination or disclosure of information for activities beyond the remit of OTA and DonateLife."

6. When I consented to the donation of Scott's organs and tissue, I did not consent to handing over ownership of Scott's donation story to DonateLife or the OTA.
7. In retrospect, I have serious doubts about whether I would have consented to the donation, if I had known that the Government would attempt to introduce such draconian measures restricting my freedom to share Scott's story.
8. I am hugely supportive of the work of DonateLife and the OTA and I have regularly, freely and happily shared Scott's story in television interviews, a documentary 'The Call', on numerous occasions as part of the training program of organ transplant nurses, launching DonateLife Week on the steps of the Sydney Opera House with the then Minister, Mark Coulton MP, to name a few.
9. I am passionate that we should be moving heaven and earth to improve the woefully low organ donation consent rates in Australia.
10. However, I am distressed and confused as to why an amendment to this Act would seek to silence donor families and limit our storytelling to four activities sanctioned by the OTA and DonateLife agencies.
11. I am also disappointed that no consultation was sought from donor families like mine, who regularly support the activities of the OTA and DonateLife; was this lack of consultation because these parties predicted the concerns from donor families that I am raising?
12. I have seen through my own advocacy work that donor families' stories have the power to increase registrations onto the Australian organ donation register, with many audience members telling me that they have signed onto the register during my storytelling.
13. Furthermore, I know of at least four additional lives saved by a former colleague who tragically passed away but had registered their wishes on the register following my storytelling at an event that I arranged at my place of work...this event was not sanctioned by DonateLife or the OTA.
14. Scott not only saved two people through his own donation, but the power of his story saved at least four more people that I know of, and there could be more given my zeal to share his story.
15. Scott's organ and tissue donation provided comfort during the early days of my grief and is an immense source of pride to me and our families.
16. I find it inhumane that legislation could be drafted in this country that would seek to silence us.

17. I should have ownership of my husband's donation story and there should be no restrictions on my ability to tell this story, ever.

Conclusion

18. In conclusion, I hope that by sharing these examples, you can appreciate my commitment to improving donation rates in Australia.
19. Donor families deserve the same respect, agency and freedom of speech that any other bereaved family, to tell their loved ones story, particularly when that story has the power to save lives.
20. Donor families have given so much through the donation of our loved ones organs, please don't take our stories from us.
21. I am happy to discuss any of the issues I've mentioned here in more detail with individual Committee members or by appearing before the Committee.

Yours sincerely,

Philippa Delahoy