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Mr Bruce McDowell
Chairman
Donor Families Australia Inc
Unit 2, 38 Preston Street
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By Email: admin@donorfamiliesaustralia.org

Dear Bruce

Donor Families Australia

Issues

- 1 You have asked Lavan to consider the proposed amendments to the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008 (Cth)* (**OTDA**) and the implications for Donor Families Australia (**DFA**) and families of deceased donors and recipients.
- 2 Lavan previously gave advice by letter of 30 April 2021 on the *Human Tissue and Transplant Act 1982 (WA)* (**HTTA**). Some minor amendments were made to HTTA in 2022, but none affects the provisions contained in our advice or the conclusions we expressed.

Legislative Framework

- 3 Organ and tissue donation is covered in both Federal and State legislation.
- 4 In Western Australia, the primary legislation is the **HTTA**, which is still in force.
- 5 At the Federal level these matters are dealt with by the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008 (Cth)* (**OTDA**).

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- 5.1 The OTDA established the Australian Organ and Tissue Donation and Transplantation Authority (**Authority**).¹
- 5.2 The Authority's function is (among other things) to support, encourage, conduct, and evaluate educational, promotional and community awareness programs that are relevant to organ or tissue donation and transplantation matters.²
- 5.3 Currently section 58 only deals with disclosure concerning the identity of donors (or recipients) by the Authority and CEO. It provides that the Authority or CEO must not publish or disseminate information likely to enable the identification of a particular organ or tissue donor (**donor**) or recipient except with the consent of the donor or recipient if aged at least 18-years or if the donor or recipient is deceased their surviving partner or in any other case an authorised individual under the OTDA. By regulation 8 of the *Australian Organ and Tissue Donation and Transplantation Authority Regulations 2020* a parent or legal guardian of a donor aged less than 18 years is authorised to give consent to the publication or dissemination of information.
- 5.4 The OTDA is expressly not intended to exclude or limit the operation of the HTTA.³ This permits the HTTA will operate alongside the OTDA except to the extent of any inconsistency. If any inconsistency does arise the OTDA will always prevail over the HTTA⁴ and where the OTDA is silent the HTTA remains the binding authority.

Summary of proposed amendments

- 6 The *Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023* (**the Bill**) proposes to amend the OTDA to (among other things) insert a section 58A – Publication, dissemination, or disclosure of patient information—DonateLife Agencies, grant recipients and authorised family members.
- 7 The Bill has been referred to a Standing Committee, which is to report by 26 July 2023.
- 8 This proposed change will allow the Organ and Tissue Authority (OTA), DonateLife Agencies,⁵ grant recipients⁶ and authorised family members⁷ to publish, disseminate

¹ Explanatory Memorandum, Australian Organ and Tissue Donation and Transplantation Authority Bill 2008 (Cth) 1.

² *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (Cth), s 11(1)(f).

³ *Ibid*, s 59.

⁴ *Australian Constitution*, s 109.

⁵ *Ibid*, s 58A(2)(a).

⁶ *Ibid*, s 58A(2)(b).



or disclose information about deceased donors for the purposes of the OTA or a DonateLife Agency's community awareness, educational or commemorative activities (**approved activities**) within Australia.⁸

- 9 The Bill defines a 'DonateLife Agency' to mean for the purpose of the OTDA; a specified agency,⁹ that has a role or function in relation to organ or tissue donation and transplantation matters, which the Minister declares is a DonateLife Agency. Before making this declaration in relation to a State or Territory department, authority or part of a department or authority consult the relevant State or Territory Minister responsible for the administration of health matters.¹⁰
- 10 It appears that the proposed amendment, if made, means that DFA may apply (although the precise procedure by which this will be done is currently unclear) to the Minister to be made a DonateLife Agency for the purpose of the OTDA.
- 10.1 To meet this definition DFA must be a 'specified agency' which under the Bill includes a body corporate. Given DFA is an incorporated association it will satisfy this first requirement.
- 10.2 DFA will likely also satisfy the second requirement given it is engaged in a role in relation to organ or tissue donation being to educate and raise awareness for donation and to commemorate deceased donors.
- 11 These amendments also expand the list of a deceased donor or recipients 'authorised family members' to include, their partner, parent (or legal guardian), child (including adopted, stepchild, exnuptial or foster child), sibling, grandparent, and grandchild.¹¹
- 12 Consequently, if DFA meets the requirements in section 5F of the Bill (if the OTDA is amended in those terms) and is declared a DonateLife Agency for the purpose of the OTDA, with the consent of an authorised family member DFA may publish, disseminate, or disclose information about a deceased donor or recipient for the purpose of approved activities.
- 13 However, we are instructed that DFA is unlikely to become a DonateLife Agency.
- 14 Consequently, these proposed amendments still do not allow authorised family members to *directly* to publish, disseminate, or disclose information capable of identifying a deceased donor or recipient. For example, a family member could not

⁷ Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 (Cth), s 58A(3).

⁸ Commonwealth, *Parliamentary Debates*, House of Representatives, 24 May 2023, 6, (Ged Kearney, Assistant Minister for Health and Aged Care).

⁹ Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 (Cth), s 5F(6)(e).

¹⁰ Ibid, ss 5F(3)-(5).

¹¹ Ibid, s 5.



go directly to a journalist to publish a story identifying their family member as a donor or recipient. The pre-existing preclusion will remain.

- 15 Instead, authorised family members must disclose their family members story to the OTA or a DonateLife Agency, who must use it for the purpose of an approved activity at which time it is capable of secondary publication.¹²
- 16 The secondary publication provision enable any person, including authorised family members and the DFA to publish, disseminate, or disclose for the purpose of reporting on an approved activity, information which has already been the subject of a publication, dissemination or disclosure by the OTA or a DonateLife Agency for an approved activity within Australia.
- 17 For example, if DonateLife WA holds a commemorative service highlighting five donor stories (with the consent of an authorised family member), a family member of one of the donors mentioned at the service could make a social media post about the event and their family member's story.

Can DFA exist as an organisation if the amendments are enforced?

- 18 DFA can continue to operate if these new amendments are passed.
- 19 Additionally, as identified above, if DFA is declared a DonateLife Agency for the purpose of the OTDA they will be able (with consent) to publish, disseminate or disclose information about a deceased donor or recipient for the purpose of an approved activity.
- 20 However, as DFA does not want to be a DonateLife Agency it appears DFA may take advantage of the secondary publication provision.¹³ This provision provides as above that if the OTA or a DonateLife Agency uses information (with consent) about a deceased donor or recipient for an approved activity, the information may then be subsequently posted or used by DFA as a secondary publisher for the purpose of reporting on the relevant approved activity.¹⁴
- 21 For example, if the OTA holds a community awareness event and hands out brochures with several donor stories (with the consent of an authorised family member), DFA could publish this information on their website disclosing the donors identities.
- 22 Proposed section 58A(6) makes it plain that the secondary publication provisions will oust any limitation on such publication contained in the HTTA.

¹² *Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023* (Cth), s 58A(5).

¹³ *Ibid*, s 58A(5).

¹⁴ *Ibid*, s 58A(5).



Do the proposed amendments to section 58 create greater restrictions on disseminating information about their (deceased) family members donation?

- 23 As noted above, the OTDA does not currently deal with the primary dissemination of information by the family members of deceased donors. Therefore, the HTTA governs this conduct. As previously advised the HTTA does not allow family members of deceased donors or recipients to discuss or publish information about the donation which is capable of identifying the donor.
- 24 The proposed amendments create an opportunity for authorised family members to publish, disseminate or disclose information for the purpose of approved activities by the OTA or a DonateLife Agency, and then, potentially, as a secondary publication for an approved purpose.
- 25 While this use is restrictive, it does not appear to create a 'greater' restriction than the current framework which does not allow any publication by the families of deceased donors or recipients.

Rights of donor families to hold the OTA/DonateLife accountable

- 26 The broad purpose of these amendments is to allow family members to share their loved one's story of organ donation with the hope of encouraging others to do the same.¹⁵
- 27 Enabling donor families to hold the OTA or a DonateLife Agency accountable was not a priority of this legislation. As such, disclosure for this purpose is not addressed.
- 28 The HTTA also does not cover this issue.
- 29 It may be possible for families of donors to hold OTA or a DonateLife Agency accountable without directly disclosing the identity of their loved one and instead raising issues more generally.
- 30 However, if this is insufficient, it may be necessary to lobby the Government to expand the rights of authorised family members to disclose the identity of their loved ones to a body other than OTA or a DonateLife Agency for the purpose of holding them accountable.

Does the legislation prohibit consenting donor families and consenting recipients seeking each other out?

- 31 In their Second Reading speech the Assistant Minister for Health and Aged Care noted 'these amendments are not intended to facilitate direct contact between donor families and organ tissue recipients. Governments intend to protect the rights of both donor families and transplant recipients to remain anonymous.'¹⁶

¹⁵ Commonwealth, *Parliamentary Debates*, House of Representatives, 24 May 2023, 6, (Ged Kearney, Assistant Minister for Health and Aged Care).

¹⁶ Ibid.



32 However, the Legislation is silent on this matter meaning it is necessary to consider the HTTA.

33 As per our previous advice, according to the 'Review of the Australian organ donation, retrieval and transplantation system - Final Report - 12 December 2018' (**the 2018 Review**)¹⁷, the purpose and context in which the HTTA operates, with respect to disclosure of identifying information, is as follows:

*The respective Human Tissue Acts prohibit the disclosure of identifying information which may result in the identification of an organ donor or transplant recipient. As a result, health professionals are not able to facilitate the meeting of donor families and transplant recipients. While the legislative provisions may vary depending on the jurisdiction, **the purpose remains the same: to protect the identity of those who have donated organs, or received.***

[emphasis added]

34 Under the HTTA, it appears that no person may give information/document(s) pertaining to a deceased donor or recipient if that person is deceased. If this is correct despite both sides consenting, they will not be able to 'seek each other out' as this would require disclosing the identity of the deceased donor or recipient.

35 However, it is arguable that if the deceased person, prior to their death, had given consent for their identifying details to be disseminated, this would fall into the exception of consent under s34(2)(c). It is unclear however, even if both sides had received consent prior to death how they could go about seeking each other out as the Act does not provide for this situation.

Can donor families disclose to other donor families what their loved ones have gifted?

36 Generally, donor families cannot directly disclose to other donor families what their family member donated.

37 However, once the information has been the subject of a publication, dissemination or disclosure by the OTA or a DonateLife Agency for an approved activity, this information is then capable of 'secondary publication' by another party for an approved activity.

Requirements for donor families and families of deceased recipients to be made aware of the legislation

38 You have raised with us whether donor families are required to be made aware of the legislation before agreeing to donation as part of making an informed consent or as part of the ethical requirements and after agreeing to donation.

39 From a legal perspective, there are no requirements in either the HTTA, OTDA or the Bill that donors and/or their families must be informed of their rights after consenting to organ donation. Under the HTTA, consent can only be given if medical advice (not legal advice) has been given.

¹⁷ Review of the Australian organ donation, retrieval and transplantation system (Final report, 12 December 2018), 106.



Can donor families appear before a Senate inquiry if this legislation is passed?

- 40 In June the Senate referred the Bill to the Community Affairs Legislation Committee **(the Committee)** for inquiry and report. The Committee is to report by 26 July 2023.
- 41 Proceedings of the Committee are proceedings in Parliament meaning parliamentary privilege applies.
- 42 Parliamentary privilege operates as an ‘immunity’ from the ordinary law. This immunity protects witnesses giving evidence in Committee proceedings from civil or criminal action, and examination in legal proceedings.¹⁸
- 43 Consequently, although family members of deceased donors and recipients typically cannot disclose information capable of identifying their loved one, they may do so when appearing before the Committee. This is true irrespective of whether the Bill is passed.

Does the government own the deceased donor and recipient information and given the Donate Life agencies have a database of all deceased donors and their families does this mean the OTA (Federal Dept) now has access to this information?

- 44 We have no information on the protocols of OTA or any DonateLife Agency regarding the holding and sharing of data between these agencies.

Are the previously state/territory controlled Donate Life Agencies now federal departments?

- 45 Section 5F of the Bill gives the Minister power to declare a specified agency a DonateLife Agency *for the purpose of the OTDA*. Agencies declared a DonateLife Agency in this way are not the same as existing state and territory controlled DonateLife Agencies.
- 46 Further, section 5F specifically requires the Minister before making such a declaration in relation to a State or Territory department, authority or part of a department or authority to consult the relevant State or Territory Minister responsible for the administration of health matters.¹⁹
- 47 Consequently, these amendments do not transform existing state or territory controlled DonateLife Agencies into federal departments.

Yours faithfully

Iain Freeman
Partner

¹⁸ *Parliamentary Privileges Act 1987* (Cth).

¹⁹ *Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023* (Cth), ss 5F(3)-(5).