

2020

**LEGISLATIVE ASSEMBLY FOR THE
AUSTRALIAN CAPITAL TERRITORY**

**BIRTHS, DEATHS AND MARRIAGES REGISTRATION (TISSUE DONOR
ACKNOWLEDGMENT) AMENDMENT BILL 2020**

EXPLANATORY STATEMENT

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OUTLINE

This explanatory statement relates to the Births, Deaths and Marriages Registration (Tissue Donor Acknowledgment) Amendment Bill 2020 (“the Bill”) as presented to the Legislative Assembly. It does not form part of the Bill and has not been endorsed by the Assembly. The statement is to be read in conjunction with the Bill. It is not, and is not meant to be, a comprehensive description of the Bill.

Purpose of the Bill

The Births, Deaths and Marriages Registration (Tissue Donor Acknowledgment) Amendment Bill 2020 proposes amendments to the *Births, Deaths and Marriages Registration Act 1997*.

The Bill provides for two opportunities for a family of a person who has donated tissue while living or on death to have this donation formally acknowledged. For the purposes of this Bill, ‘tissue’ includes an organ, or part, of a human body or a substance extracted from, or from a part of, the human body as per the *Transplantation and Anatomy Act 1978*.

The first opportunity for recognition is that, on request in writing by a next of kin of the deceased person, together with verifying information, the registrar-general must include in the death register a statement that the person was a tissue donor. Only information that is in the death register can be included on a death certificate issued by the registrar-general. On the occasion of this information being entered into the death register, families can then apply for a death certificate which reflects—or correct a death certificate to reflect—that the deceased person was a tissue donor.

The second opportunity for recognition is that, as part of the above request, a next of kin can further request to receive an acknowledgment letter that the deceased person was a tissue donor from the Chief Minister of the Australian Capital Territory. A letter from the Chief Minister is intended to reflect the significance of the donation and the family’s decision.

Both recognition opportunities are optional and made only at the request of next of kin. These recognition opportunities are available to be applied for at any time, including if the deceased person who was a tissue donor died prior to the commencement of this Act.

Background

Tissue donation is where tissue is retrieved from a donor and transplanted into a recipient. Tissue donation can occur when the donor is deceased (after brain or cardiac death) or living. According to the Australian Government Organ and Tissue Authority, around 1400 Australians are currently waitlisted for a transplant, and many more would benefit.

The decision to donate tissue is a significant one and it is appropriate to recognise the significance of this gift in a formal way.

There currently exist a number of avenues in the Australian Capital Territory through which tissue donation is recognised, including services of remembrance, the Gift of Life walk and the Gift of Life garden at the National Arboretum. This Bill provides for two further formal and material opportunities for families to have the tissue donation of their loved one recognised, if they so wish.

Interaction with Federal Law

Nil. The registration of deaths and the provision of death certificates is the responsibility of state and territory governments in Australia.

Human Rights Considerations

This Bill potentially engages a person's right:

- (a) not to have his or her privacy, family, home or correspondence interfered with unlawfully or arbitrarily; and
- (b) not to have his or her reputation unlawfully attacked

These rights are engaged due to the disclosure of the deceased's personal information to the registrar-general and this information being contained on the death register. These rights are also engaged due to the disclosure of information, via the registrar-general, to the Chief Minister.

The disclosure of this information, if the next of kin desires, is for the purposes of recognition in a formal way that the deceased person was a tissue donor. The limitation is necessary for the purposes of:

- verifying the identity of the deceased person
- providing verifying information that the deceased person was a tissue donor
- providing the name and address of the deceased person's next of kin so that they may receive a letter of acknowledgement from the Chief Minister

This statement does not intend to adjudicate that the deceased person has privacy rights. However, to the extent that the right to privacy is potentially engaged, the disclosure of personal information of the deceased person and/or the next of kin is voluntarily made by the next of kin. The disclosure is not mandatory. By the disclosure only being made by the next of kin, this limits the number of individuals engaged in the disclosure. Further, the registrar-general's powers under the *Births, Deaths and Marriages Registration Act 1997* are subject to limitations that protect the privacy of individuals about whom records are held. The death register is not public except for information that is more than 30 years old. These are the least restrictive means of providing the information for the purposes of formal recognition and there are limited opportunities for the deceased person's, or the next of kin's, personal information to be handled or disclosed inappropriately.

For these reasons any limitations on the right to privacy are reasonable, justified and proportionate.

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DETAIL

Clause 1 – Section

This clause names the Act as the *Births, Deaths and Marriages Registration (Tissue Donor Acknowledgment) Amendment Act 2020*.

Clause 2 - Commencement

This clause provides that the Act commences on the day after its notification day.

Clause 3 - Legislation Amended

This clause identifies the legislation amended by the Act.

This Act amends the *Births, Deaths and Marriages Registration Act 1997*.

Clause 4 – New section 38A

This clause inserts a new section 38A which provides two options for the next of kin of a deceased person who was a tissue donor to have this tissue donation formally recognised.

Subsection (1) provides that these options are available whether the death has already been registered or is to be registered.

Subsections (2) and (3) provide that the registrar-general must include in the death register that the person was a tissue donor if the next of kin makes a request in writing accompanied by verifying information. ‘Verifying information’ is not defined but would be likely to include, for example, acknowledgment letters and consent forms relating to the tissue donation.

Subsection (4) provides that, if the next of kin has made the request as per subsections (2) and (3), they have an additional option of requesting a written acknowledgment from the Chief Minister via the registrar-general, provided that they make this request in writing with their name and address. Subsection (4) (b) provides that the registrar-general must give this request to the Chief Minister.

Subsection (5) defines ‘next of kin’ as per the definition provided in the *Transplantation and Anatomy Act 1978* dictionary. It further defines ‘tissue donor’ as a person who had tissue removed from their body while they were living or after death with consent, in accordance with the *Transplantation and Anatomy Act 1978*.