



Information for donor families and transplant recipients regarding direct contact

The purpose of this document is to provide information of a general nature only. This information may assist families of deceased organ and tissue donors (donor families) and transplant recipients (recipients) who may wish to pursue direct contact. The document is not intended to represent the views of the Organ and Tissue Authority (OTA) or any government agency.

It is acknowledged that people are finding their own ways to identify and meet each other, particularly through social media and other ways such as personal details from news reports. In recognition of the different, and at times conflicting, views associated with meeting of donor families and transplant recipients, this document hopes to provide useful information for those people who are considering direct contact. In providing this information the OTA is not recommending a particular course of action. Individuals' circumstances and experiences will vary case by case. The potential risks and benefits that may be associated with seeking direct contact outlined in this information are not intended to be exhaustive or to represent the experiences of all donor families or transplant recipients. This document is intended to provide information on three broad areas:

- + Australian legislative frameworks for the donation of organs and tissues
- + Australia's system for correspondence between donor families and transplant recipients
- + Issues donor families and transplant recipients may wish to consider prior to seeking to meet their respective donor family or transplant recipient

Legislation

Respect for privacy and confidentiality is a key ethical principle of modern healthcare. In Australia, it is currently not possible for health professionals, the OTA or DonateLife staff to facilitate the meeting of donor families and transplant recipients as this would require the disclosure of identifying information, which is prohibited by law in all Australian states and territories.

In Australia, the donation of organs and tissues for the purpose of transplantation takes place within a legal context. Under Australia's federal system, regulation of organ and tissue donation is the responsibility of the states and territories under relevant legislation (referred to here as 'Human Tissue Acts') and associated regulations that govern dealings with human tissue. Legislation is similar across the states and territories, though not identical. The information contained in this document is not intended to provide advice on the operation of the various state and territory legislation. You should seek your own legal advice as required.

The Human Tissue Acts generally set legal requirements for the certification of death; consent to donation; donation of organs, eyes and tissues; and disclosure of information about donors and recipients. Specific provisions within each of the state and territory Human Tissue Acts prohibit the disclosure of information by which the identity of an organ or tissue donor and/or transplant recipient may become publicly known. This includes information that could lead to the identification of a person, not necessarily just the names of donors and recipients.

While the provisions are different in each state or territory Human Tissue Act, they all have the same intent: to maintain confidentiality and protect the identity of those who donated organs and tissues, and the identity of those who receive transplants. The Human Tissue Acts operate alongside the relevant privacy legislation or privacy policies of the jurisdictions.

Any change to Human Tissue Acts or policy is a matter for the relevant state and territory governments.

Australia's system for correspondence between donor families and transplant recipients

In Australia, donor families and transplant recipients may write anonymous letters or cards to each other. Written communications are exchanged under the oversight of DonateLife Agencies and transplant units in each state and territory who take care to ensure that there are no potentially identifying details in the correspondence in order to meet legislative obligations as outlined above.

The decision to write is a very individual and personal one. It may take months or even years before a donor family or transplant recipient is ready to send and/or receive correspondence. It could be the case that no correspondence is entered into by either the donor family or transplant recipient.

As part of the [National DonateLife Family Support Service](#), correspondence guidelines have been developed to assist both donor families and transplant recipients when writing.

Direct contact between donor families and transplant recipients

Some individuals and community groups have been advocating for changes to Australian policy to enable direct contact between donor families and transplant recipients.

The OTA has undertaken a number of activities to look into the area of direct contact between donor families and transplant recipients, including the development of an issues paper in March 2017 and hosting a community consultative forum. These activities provided opportunities for sharing and open discussion which included donor families, transplant recipients, government representatives, and health professionals, and identified a range of different perspectives and insights into the complex issue of direct contact between families and recipients. The [report on the community consultative forum](#) (which includes the issues paper) is available on the OTA's website.

This work has identified that there are a variety of views associated with the meeting of donor families and transplant recipients. Some groups wish to maintain privacy, others want to meet, and some groups are unsure of their feelings on the issue.

Direct contact: Things to consider

In researching experiences internationally and through the work done in Australia (see [report on the community consultative forum](#)), the following common potential benefits and risks in direct contact for both the donor family and the transplant recipient were identified.

Potential benefits

For the **donor family**, some of the potential benefits of direct contact may include providing:

- + an opportunity to share information about their family member with the transplant recipient
- + reassurance that donating was the right decision
- + a sense of closure and peace
- + assistance in the grieving process.

For the **transplant recipient**, some of the potential benefits of direct contact may include providing an opportunity to:

- + express their gratitude for the donor and donor family's generosity
- + convey their sorrow for the donor family's loss
- + find out more information about the donor as a person.

Potential risks

For the **donor family** and **transplant recipient**, some of the potential risks of direct contact may include:

- + that contact is not desired by the other party
- + increasing grief or guilt for the donor family or recipient
- + that, once contact is made, anonymity is lost and there may be difficulty in controlling the level of contact desired
- + if something happens to the recipient, there can be a sense of grief or secondary loss for the donor family
- + for the transplant recipient there may be a feeling of guilt that they are alive rather than the donor
- + that one party may want to broadcast the information on social media which may make the other party uncomfortable with having pictures or private information posted
- + expectations of the other party that may not match up to reality leading to disappointment
- + incorrect assumptions that the match with the other party is correct
- + although rare, there may be coercive and unpleasant practices such as seeking financial support or stalking.

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The following information is based on the research of international experiences and the work done in Australia (see [report on the community consultative forum](#)), and may be useful to consider before making a final decision about direct contact.

- 1 Professional counselling:** It may be helpful to seek professional counselling to discuss the matter. Counsellors may be able to help by talking through your reasons for wanting to make contact and any expectations or concerns you may have.
- 2 Respect the other person's rights to privacy:** It may be possible that the other party has no interest in making contact, and may not respond to your communication.
- 3 Take time before meeting in person:** If the other party is interested in meeting, it may be useful to take some time to communicate in other ways, such as writing to each other. During this time you can find out about each other and then decide if meeting face to face is really what you want to do. Once both parties have decided to make contact, you might consider meeting in a neutral location so there is no pressure placed on either party.
- 4 Media interest:** It may be possible that the general media become aware of the direct contact that you have made and will ask you and/ or the other party to share your story further with the general public. Once you share your story, other people may want to know more details and may become persistent. This may be difficult for you, your family, and the other party and their family.
- 5 Social media:** Some donor families and transplant recipients may wish to share the contents of correspondence they may have received via social media. The correspondence is usually of a very personal nature and likely to contain private expressions of deep gratitude or feelings, and for some there may be an element of trust that the personal message is being kept safe. Once correspondence has been placed on social media, it is unlikely to remain anonymous and de-identified. Thought should be given before sharing any correspondence in a public manner without the explicit permission of the author of the correspondence.

Individual circumstances and experiences will vary on a case-by-case basis. The information in this document is of a general nature only and is provided to assist individuals in considering their own circumstances.