



Donor Families
AUSTRALIA



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donorfamiliesaustralia.org



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DONOR FAMILIES AUSTRALIA

Donor-Recipient Contact Register

Contact Process and Conditions

IMPORTANT:

Before completing your Register Application Form, you must:

- 1. Be confirmed as a Member (Donor Family) or Associate Member (Recipient) of Donor Families Australia, AND**
- 2. Read and acknowledge your acceptance of the process and conditions in this document – this is confirmed by ticking the appropriate box in the online Register Application Form.**

Dear Donor Families Australia Member or Associate Member (Recipient)

The Donor and Recipient community has requested that Donor Families Australia Inc. (also referred to as *DFA* in this document) act as a 'conduit' to facilitate connections between Donor Families and the beneficiaries of their deceased family member's donation (also referred to as *Recipients* in this document. In the experience of DFA, these relationships have demonstrated benefits for those involved. DFA has therefore responded by agreeing to DFA Member's requests to provide a facilitation role to enable adult mutually consenting Donor Family Members and Associate (Recipient) Members to connect.

The process to connect Donor Families with Recipients has been developed in consultation with people who have experienced the benefits of these relationships within the DFA community, and with others who recognize the potential risks involved. A process that allows DFA to act as a conduit for information sharing between consenting adults who have been part of a donor-recipient experience and wish to meet, has been endorsed by its National Committee of Management. This has required DFA to establish a confidential, secure Donor-Recipient Contact Register to store and manage personal information for use in facilitating mutually consenting individuals to connect. This service is available to all registered DFA adult members, both Donor Families and Associate (Recipient) members, following the receipt of a written agreement for the individuals' personal details and information about their donor and/or recipient experience to be added to the DFA Donor-Recipient Contact Register and then:

1. matched if possible; and
2. following mutual agreement of both parties,
3. shared with the matched donation / transplantation consenting parties.

Important:

There is **NO** obligation to participate in this Register. Participating in the Donor-Recipient Contact Register is a voluntary decision that's made by the adult individual(s) involved. Consent to the storage or use of information provided to the DFA Donor-Recipient Contact Register can be

withdrawn at any time. It is the personal choice of each adult member / associate member if they wish to participate or not. Clearly this register requires consent from both parties before connections can be identified or facilitated. Further, DFA can give no assurance that the other party involved in the donation/transplantation experience will:

1. know about the existence of DFA or the Register; or
2. know about the possibility that they can register or connect; or
3. feel comfortable about registering their personal information, or
4. agree to connect if a potential match is identified.

Although the personal details that pertain to the donation and/or transplantation may appear to match a donor and recipient, DFA can give no assurances that the match is correct. For example, it's not unusual for a 'cluster' of donation activity to occur—whereby several deaths and donations may occur simultaneously across the country, providing benefit to many recipients from different donation situations. Also, it's important to understand that depending on complex circumstances there may be periods of up to at least three days between the date of the deceased donor's death and the transplant of organs with much longer periods following tissue donation.

DFA provides this consumer led service independent of DonateLife and other healthcare organisations. This is because legislative and policy barriers preclude some healthcare organisations from helping interested donor family members and the recipients of their deceased relatives donation from connecting.

Most importantly, it is not illegal nor does it breach confidentiality, for an individual to provide their personal details about surgery or details about the death of their deceased relatives to a third party, in the hope that such information may facilitate contact between consenting adults who have been part of a donation-transplantation experience. Evidence of the rights of individuals to publish such material can be seen in the death notices and news items regularly available in print and other media sources.

Potential Risks

It's known that most people experience benefits in meeting, however, it's important to consider the possible risks that may be involved in connecting consenting Donor Families and consenting Recipients and their families. The risks may be at an emotional and psychological level, but may also involve other aspects of individuals and family's social and emotional well-being. **It's not possible to foresee all the risks and possible implications for these meetings.** Some known risks that should be considered before making a decision to share your personal information on the DFA Donor-Recipient Contact Register include:

- Because organ and tissue transplantation is a treatment (not a cure) to help people suffering from a range of chronic and life-threatening health conditions, it's possible a Donor Family could suffer additional grief if they became aware that their known recipient were to die or suffer ill health;
- If either the Recipient or Donor Family did not match the expectations of the individuals involved;
- Donor Families and/or their recipient(s) may become upset or disappointed if the other's beliefs, social circumstances, religion, nationality, or social connections are different to their own;
- It's possible that normal personal boundaries may be unwittingly broken if an individual seeks to intrude in an unwelcome way into the other's life - including seeking to become involved in their personal health, relationships and activities;

- Or Recipients and their family may feel a sense of obligation to the relationship because of the impact of the donation;
- Either party may be unaware of the complex circumstances surrounding their own experiences of the donation / transplantation and may feel that there is insensitivity in the communication;
- The Recipient may struggle with a sense of guilt when connecting with their Donor Family, because the family they're meeting has suffered a bereavement;
- The possibility that after the meeting, each party may have differing views about continuing to stay connected. For example, one party may be perceived as dominating the other, and the other may wish to withdraw from or limit communication.

It should be noted that in the known instances where consenting Donor Families and their Recipients have met in a planned way, **to the knowledge of DFA, meetings have been successful and found to benefit all involved**. However, both parties must always be aware of the personal risks involved in such a meeting regardless how remote they may seem. To this end DFA takes no responsibility as to the outcome of each meeting.

Connection Guidelines

The following are guidelines for the management of donor-recipient contact.

1. The Donor-Recipient Contact Register is only available to Members (Donor Families) and Associate Members (Recipients) of Donor Families Australia.

If you have not already joined Donor Families Australia, please follow this link to apply for membership: <https://www.donorfamiliesaustralia.org/join-us>

2. In the first instance, individuals who wish to be matched are required to acknowledge their Consent which provides detailed personal information and permission for their personal data to be added to the DFA Donor-Recipient Contact Register.
3. It's important for all involved to understand that a match cannot be considered unless both Donor Family and Recipient have provided matching information and authorisation for their details to be added to the DFA Donor-Recipient Contact Register.
4. The information held within the Donor Families Australia Contact Register (DFACR) will be held in confidence securely and will only be used to match adult consenting donor families with their respective adult consenting recipients.
5. Personal information that has been provided for use on the DFACR will be withdrawn and destroyed upon the written request of those who have provided the information.
6. **This is a voluntary service that is facilitated by DFA using information provided by DFA members and associate members.** DFA does not have access to medical records involving either party and **does not** seek this access. But be aware that these information gaps will potentially limit the possibility, accuracy and timeliness of pairings.

Those participating in the DFA Donor-Recipient Contact Register are requested to provide as much information as they feel comfortable regarding their experience as a Donor Family or Recipient. Helpful information may include:

For the Donor Family

- a. The date of your loved one's donation;
- b. Your understanding of the date of your Recipient's transplantation;
- c. The age / age range of the Recipient involved and the location of the transplantation surgery;

For the Recipient

- a. The date of your transplantation;
- b. Your understanding of the date of your Donor's donation;
- c. The age / age range of the Donor involved and the location of the donation surgery;

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|---|--|
| <p>d. Your Recipient's gender: male or female;</p> <p>e. Organs and / or tissue donation</p> <p>f. Your Recipient's location (City e.g. Adelaide), State (e.g. WA) OR, Interstate</p> | <p>d. Your Donor's gender: male or female;</p> <p>e. Organ and / or tissue received;</p> <p>f. Your Donor Family's location: City (e.g. Adelaide), State (e.g. WA) OR, Interstate.</p> |
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It is absolutely essential that you include letter/s or correspondence sent to and/or received from your Donor Family or Recipient. This may include:

- i. a copy of a letter(s) or card attached;
- ii. an extract such as an opening sentence; or
- iii. content that may be unique to the Donor or Recipient (e.g. their work/ hobbies or other personal details).

Please Note: correspondence copies can be forwarded to DFA by the following methods:

- **Contact Register:** Attach your file(s) to the electronic Contact Register application form, noting the 10MB per file size limit)
- **Email via PC/laptop:** Scan items and attach to email at admin@donorfamiliesaustralia.com
- **Email via Mobile:** Photograph pages on mobile phone. Go photo gallery and tag multiple photos and press Share. Select mobile email application (eg Gmail) and send to admin@donorfamiliesaustralia.com
- **Mail:** Photocopy and post to:

Donor-Recipient Contact Register
Donor Families Australia Inc.
C/- 582/8 Carrak Road
Kincumber NSW 2251

7. **If information obtained indicates a possible match**, both parties will be contacted individually by a DFA Committee of Management Member associated with the Register, to confirm if they are still interested in making contact. Both parties must have first agreed to connect before any details between the two can be negotiated and divulged.
8. Those involved will again be advised of the possible risks involved with connecting prior to any meeting.
9. Information held by DFA will be checked and details confirmed such as: determining each party first preference to connect or share information to enable a postal, e-mail exchange, or phone contact.

This communication may lead to face-to-face contact as negotiated between the individuals. DFA recommend that this should be arranged to take place in a public location in the first instance such as a coffee shop etc. either chaperoned by a friend or family member or privately. DFA members may be able to provide some advisory or personal support based on availability and suitability of resources.

It is important to remember that a range of expert counselling support services are available for individuals through:

- The Compassionate Friends: <https://www.thecompassionatefriends.org.au>
- Donatelife: <http://www.donatelife.gov.au/donor-family-support-services>
- LifeLine: <https://www.lifeline.org.au>
- BeyondBlue: <https://www.beyondblue.org.au>

You will be asked to acknowledge that you have read, understood and accept the contact process and conditions described in this document (by placing a tick at the appropriate field) before completing the rest of the Contact Register Application Form. You will not be able to proceed with the remainder of the application process without having done this.

Before final submission, you will be asked to enter your name as an indication of your having completed and accepted all entries that you have made in your application. There is also provision to upload a copy of your signature.

For further enquiries, please direct questions to admin@donorfamiliesaustralia.com