



NATIONAL STANDARD OPERATING PROCEDURES FOR DONOR FAMILY AND TRANSPLANT RECIPIENT CORRESPONDENCE

THE ORGAN AND TISSUE AUTHORITY

DONATELIFE AGENCIES

AUSTRALASIAN TRANSPLANT COORDINATORS ASSOCIATION

TRANSPLANT NURSES' ASSOCIATION

Version 1.0

OTA – DONATELIFE AGENCIES – ATCA – TNA – NATIONAL SOP 001/2017

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1. INTRODUCTION

It is commonly recognised that bereaved people often experience a strong need for continuing bonds with the deceased. Within the milieu of organ donation and transplantation a unique link does exist and the receipt of personal correspondence from a transplant recipient or donor family is universally cited as highly valued by the family of the donor and is commonly described by donor families as '*comforting and reassuring*'.

In Australia, donor families and transplant recipients can write anonymous letters to each other via the DonateLife Agency and/or hospital transplant units in respective states and territories. In line with this, it is important that there is an effective system in the recording of incoming and outgoing correspondence to ensure the correspondence reaches its intended destination.

Parties involved in developing the National Standard Operating Procedure (SOP) for Donor Family and Transplant recipient correspondence include the Organ and Tissue Authority, Donor Family Support Coordinators in the DonateLife Agencies, the Australasian Transplant Coordinators Association and the Transplant Nurses Association.

2. PURPOSE

To enable consistency in communication procedures undertaken by DonateLife Agencies (DLA) and Transplant Coordinators, this national SOP documents the procedures of how communication between donor families and transplant recipients should be managed by DLA and Transplant Coordinators.

3. SCOPE

The National SOP applies to de-identified written communication between transplant recipients and donor families.

4. RESPONSIBILITY

Organ and Tissue Authority (OTA)

The OTA is an independent statutory agency within the Australian Government Health portfolio, established by the [Australian Organ and Tissue Donation and Transplantation Authority Act 2008](#), (the Act). The vision of OTA is to establish Australia as a world leader in best practice organ and tissue donation for transplantation that optimises every potential donation opportunity to increase access to life-transforming transplantation for Australians. The mission of OTA is to deliver a highly effective national organ and tissue donation system with the support of Australian governments, the clinical profession and the community.

The OTA works with states and territories, clinicians and the community sector to deliver the Australian Government's national reform program to improve organ and tissue donation and transplantation outcomes in Australia. Donation agencies play a vital role in providing the infrastructure necessary to facilitate the exchange of anonymous correspondence between the two parties within the constraints of the legislative boundaries of each state and territory. A National DonateLife Family Support Service has been established to provide support to families of organ and tissue donors after donation. This service provides support that is respectful and responsive to the needs of each family.

Under this SOP, the OTA will work with the DLA, the Australasian Transplant Coordinators Association (ATCA), and the Transplant Nurses' Association (TNA) in coordinating input and maintaining the currency of the document.

DonateLife Agencies (DLA)

DonateLife Agencies (DLA) are located in each state and territory and are responsible for coordinating all organ and tissue donation activity across their jurisdiction. DLAs work together with hospital staff to provide and encourage best practice to increase donation rates and aims to raise awareness about organ and tissue donation, encourage discussion about donation, offer compassionate support to donor families and manage effective services in organ and tissue donation.

Within the DLA, a Donor Family Support Coordinator (DFSC) is available to support donor families during their time of loss. The DFSC is there to listen to the family, provide information and reassurance and to answer any questions or concerns. Counselling or referral to local grief counsellors is provided if preferred. The DFSC is also responsible for the management of correspondence between donor families and transplant recipients, and in particular, undertakes the following:

- formally records receipt of correspondence from donor families and forwards it to the transplant unit, who in turn will forward it to the transplant recipient; and
- formally records receipt of correspondence from transplant recipients provided by transplant units, and then forwards it to the donor family.

Australian Transplant Coordinators Association (ATCA)

The ATCA is committed to leading, representing and supporting the specialists who are intrinsic to the success of the organ and tissue donation and transplantation process. Under this SOP, ATCA will be responsible for reviewing procedures on an ongoing basis, ensuring that it is distributed to all relevant staff via webinar and through their website.

Transplant Nurses' Association (TNA)

The TNA is committed to providing the highest attainable patient care for all transplant recipients. Under this SOP, TNA will provide consistent communication to its members regarding the concise documentation of correspondence received from donor families and transplant recipients through local education seminars and electronic correspondence. This will be aided by a standard data collection template to aid documentation and transparency. The TNA will also advocate that members follow the recommended guidelines regarding the handling of correspondence as outlined in the DonateLife Correspondence Guidelines for donor families and transplant recipients and provide ongoing education and support to its members regarding correspondence through regular state branch education seminars and the annual conference. The TNA is committed to continuing its work with OTA and ATCA to ensure the SOP is practiced by its members.

5. PROCEDURES

Donor families and transplant recipients can write anonymous letters to each other through the DLA and transplant units. The confidentiality of both the family of the donor and the transplant recipients needs to be maintained as this is the current legal requirement in all states and territories.

As part of the National Donor Family Support Services, correspondence guidelines are available for donor families and transplant recipients (available in hard copy and online at <http://www.donatelife.gov.au/donor-family-support-services>). The guidelines provide suggestions on the importance of maintaining confidentiality, the process for exchange of correspondence, what to write and information on how the letter reaches the intended person.

5.1 DonateLife Agencies – Communication Procedures

The DLA staff member in each state and territory is responsible for:

- contributing to the development, implementation, monitoring and reporting of the National DonateLife Family Support Service (NDFSS) Guidelines;
- coordinating the NDFSS within the agency and jurisdiction;
- ensuring that all families of potential and actual organ and/or tissue donors receive the support they need consistent with the NDFSS Guidelines;
- reporting and evaluating all national and local donor family support activities in the jurisdiction in accordance with agreed national performance measures; and
- working with OTA to support research projects such as the Donor Family Study.

DLA management of correspondence from transplant recipients to donor families

Note: Practices may vary from paper based to electronic files. Please adapt the below points depending on the system in use.

1. Enter details of correspondence into the data base for correspondence (refer example at [Appendix 1](#)).
2. Check the identity of the recipient matches the donor details.
3. Ensure content of correspondence excludes identifying information as stated in the National Correspondence Guidelines for Transplant Recipients.
4. Ensure the donor family has expressed a desire either verbally or in writing that they wish to receive such correspondence ([Appendix 2](#)) or by indicating verbally during follow up contact.
5. In the case of correspondence being received by the DLA where knowledge of donor family wishes are not known, attempts should be made to contact them to ascertain their decision about receiving such correspondence. Contact to the donor family could be made via telephone call/email (if known) and the outcome documented in notes. Alternatively, contact could be made by via posting the letter and documenting the returned response ([Appendix 3](#)).
6. A photocopy of the correspondence should be placed in the donor file.
7. When correspondence is received from recipients belonging to an interstate donor family the same process should be followed as above and the correspondence forwarded to the appropriate DLA accompanied by an explanatory memo ([Appendix 4](#)).
8. The DLA will provide a cover note with the recipient correspondence to be forwarded onto the donor family identifying the type of transplant. A copy of the cover note will be maintained in the donor file.

9. It is often necessary to make several copies of the correspondence to forward to individuals within the family. In the case of separated parents of a deceased child it may be appropriate to alternate the original and the photocopy of correspondence between the two parties if this is agreeable to them both.
10. If contact is not possible for reasons such as change of address, the transplant recipient coordinator should also be informed that it cannot be passed on at this time. The correspondence will be filed on the donor file.

NB: If a DLA receives correspondence from an interstate DLA or Transplant Unit and there is identifying information included, it is the responsibility of the DLA to contact the interstate DLA or Transplant Unit and request an amended version.

DLA management of correspondence from donor families to transplant recipients

When donor families seek to correspond with the transplant recipient, either in response to a letter/card they have received or to make initial contact. The DLA will provide the family with a copy of *the National Correspondence Guidelines for Donor Families* to assist them. Upon receipt of the correspondence and there are no identifying details included, the following steps should be undertaken by the DLA.

1. Enter details of correspondence into the data base for correspondence (refer example at [Appendix 1](#)).
2. Check the identity of the donor family matches the recipient details.
3. Ensure content of correspondence excludes identifying information as stated in the National Correspondence Guidelines for Donor Families.
4. Address the correspondence to the appropriate transplant unit.
5. Photocopy correspondence and place copy in donor file.
6. Enclose covering memo with correspondence ([Appendix 5](#)).
7. The details of the correspondence are recorded in the family support data base.
8. If correspondence is received from donor families belonging to an interstate transplant recipient, the same process should be followed as above and the correspondence forwarded to the appropriate DonateLife Agency/Transplant Coordinator/ Social Worker accompanied by an explanatory memo ([Appendix 5](#)).

If the correspondence contains any identifying information, DLA will contact the donor family and advise that the correspondence cannot be forwarded in its current form. Donor families will be required to either consent to the identifying information being removed or providing updated correspondence.

NB: It is the final responsibility of the Transplant Coordinator to manage the flow of correspondence and if issues arise they should contact the appropriate DLA.

DLA management of correspondence arriving more than 5 years after donation.

It is not uncommon for correspondence to arrive more than 5 years after donation (and up to 25 years post-transplant). Transplant recipients previously unaware of the possibility of writing, or the process involved may suddenly decide to write. Given the length of time since the donation, there may be a lack of awareness of the current situation of the donor family, and the following steps should be undertaken:

1. Check the identity of the donor matches the recipient details.
2. Obtain donor notes and familiarise yourself with the details of the case.
3. Attempt to ascertain if the family is still registered with the same address. If not, place the letter in the file and let the sender know that we no longer have a contact for the family.

4. If the family details are unchanged, that is, the name relates to the address and phone number consider the following steps:
 - a. Contact the family via telephone/email or by post and document the outcome – acknowledging that it is “some time since you would have had any correspondence from us, but we have received a letter/card etc.” and invite them to contact us if they wish for it to be forwarded on (enclose a prepaid envelope and a card ([Appendix 2](#)) for them to indicate willingness to receive).
 - b. Await response. If no response – file correspondence as above or send on correspondence if desired.
 - c. The details of the correspondence are recorded in the family support data base.

5.2 Transplant Recipient Coordinators – Communication Procedures

The transplant recipient coordinator is responsible for the coordination of care for transplant patients, living donors, and their families.

Steps to take when correspondence from a donor family to a transplant recipient is received in the Transplant Unit

Upon receipt of the correspondence, the transplant coordinator should undertake the following steps:

1. Enter details of correspondence into the Transplant Unit data base for correspondence, or similar (refer [Appendix 6](#) for an example).
2. Ensure content of the correspondence excludes identifying information as stated in the *National Correspondence Guidelines for Donor Families*.
3. The correspondence is then forwarded to the transplant recipient and recorded on the Transplant Unit data base, or similar. (Whilst the treating team may consider the transplant recipient is not ready for any correspondence, any decision on when to open and read the correspondence should only be made by the transplant recipient.)
4. The transplant coordinator then sends an email to the DonatLife contact confirming the correspondence has been sent to the transplant recipient.

NB: If a Transplant Unit receives correspondence from an interstate DLA or Transplant Unit and there is identifying information included, it is the responsibility of the DLA to contact the interstate DLA or Transplant Unit and request an amended version.

Steps to take when correspondence from a transplant recipient to a donor family is received in the Transplant Unit

Upon receipt of the correspondence, and there is no identifying information included, the transplant coordinator should undertake the following steps:

1. Enter details of correspondence into the Transplant Unit data base for correspondence, or similar (refer [Appendix 6](#) for an example).
2. Record the date of receipt of correspondence in from the transplant recipient on the Transplant Unit data base, or similar.
3. Ensure that the content of the correspondence excludes identifying information as stated in the *National Correspondence Guidelines for Transplant Recipients*.

4. The correspondence is then forwarded to the Donatelife contact and recorded on the Transplant Unit data base, or similar, and the transplant recipient is informed that the correspondence has been sent.

If the correspondence contains any identifying information, the transplant coordinator will contact the transplant recipient and advise that the correspondence cannot be forwarded in its current form. The transplant recipient will be required to either consent to the identifying information being removed or provide amended correspondence.

APPENDIX 1

DONATELIFE AGENCY – EXAMPLE OF DATA BASE FOR CORRESPONDENCE – DONOR FAMILY AND TRANSPLANT RECIPIENT

Reference / File Number	Donor Name	Donor Family Contact Name	Donor Family Contact details (Address, phone, email)	Date Donor Family Correspondence is received for Transplant Recipient	Correspondence is checked to ensure no contact name or details are included (Tick)	Date Donor Family Correspondence is forwarded to Transplant Unit	Date Transplant Recipient Correspondence is received for Donor Family	Correspondence is checked to ensure no contact name or details are included (Tick)	Date Transplant Recipient correspondence is forwarded to Donor Family

Template - Correspondence from Transplant Recipients



Correspondence from Transplant Recipients

Recipients are truly grateful

Many have said that they are overwhelmed with emotion and have difficulty in expressing their feelings in words

If, in the future we receive any correspondence from the recipients helped by your loved one, would you like us to forward this on to you?

- I would like any correspondence forwarded to me
- I would prefer not to receive correspondence*

Please tick the above boxes as appropriate, complete the details as below and return it in the pre-paid envelope

Name.....

Address.....

Name of your relative/partner/child who helped others through organ donation

* If in the future you change your mind, please feel free to contact us.

Template – Letter to Donor Family regarding card from transplant recipient

Name and address

Date

Dear

We have received a lovely card from one of the very grateful persons helped by..... through kidney transplantation. In keeping with the legislation under which we work the correspondence does not reveal their identity, but their gratitude is very evident in their chosen words.

As I am not aware of your wishes regarding receiving such correspondence, I would be very grateful if you could complete the enclosed card and return it to me if you wish me to forward it on to you. If you would rather not accept it at this time I will keep it on file.

Please do not hesitate to contact me on the numbers below if I can be of assistance in any way.

With kind regards,

DonateLife Agency

[Insert phone number and/or email address]

Template – Cover memo: Letter from Transplant Recipient to Donor Families

Dear.....

Please find enclosed a thank you card from recipient of afor your donor family number:

The date of transplant was.....

Kind regards

DonateLife Agency



Template – Cover memo: Letter from Donor Families to Transplant Recipient

Dear.....

Please find enclosed a thank you card from the donor family for your recipientwho received a transplant.

The date of transplant was.....

Kind regards

DonateLife Agency



APPENDIX 6

Transplant Unit – Example of Data base for Correspondence from Transplant Recipient and Donor Family

Ref/ File number	Transplant Recipient Name	Transplant Recipient contact details (Address, Phone, Email)	Date and Type of Transplant	Donor number	Confirmed correct match	Date Transplant Recipient Correspondence is received for Donor Family	Correspondence is checked to ensure no contact name or details are included (tick)	Date Transplant Recipient Correspondence is forwarded to Donor Family via DLA	Date Donor Family Correspondence is received for Transplant Recipient	Correspondence is checked to ensure no contact name or details are included (tick)	Date Donor Family correspondence is forwarded to Transplant Recipient

Version Control

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