



Letter Writing Exchange Review Improvements

In 2020, the Organ and Tissue Authority (OTA) and DonateLife led a consultative review of the Correspondence Guidelines for donor families and transplant recipients and the National Standard Operating Procedure (SOP) for managing the exchange of correspondence between donor families and transplant recipients. The purpose of this review was to strengthen the procedures, facilitate a robust and accountable process for managing correspondence between DonateLife Agencies and Transplant Units and better reflect the needs of both donor families and transplant recipients.

The OTA's Community Engagement Group, of which Donor Families Australia is a member of, were asked to review and provide feedback on the revised Correspondence Guidelines and National SOP. Donor Families Australia consulted with its members and provided comprehensive feedback to the OTA which was considered in great detail.

The following changes have been incorporated to the Correspondence Guidelines and the National SOP by the OTA and DonateLife following the feedback provided by Donor Families Australia:

- 1** The letter writer will be contacted twice; at the point of letter receipt and at the conclusion of the letter writing process by the DonateLife Agency or Transplant Unit. Specifically this means that donor families and transplant recipients will be contacted at the following points:
 - a** When their correspondence has been received by the relevant DonateLife Agency/Transplant Unit and forwarded to the respective Transplant Unit/DonateLife Agency; and
 - b** When their correspondence has then been sent to the intended donor family/transplant recipient by the Transplant Unit/DonateLife Agency.

The implementation of this policy will give confidence to letter writers that their letters have been received and are being processed in an efficient and accountable manner.

- 2** DonateLife Agency and Transplant Unit staff will not change a letter unless there is specific consent from the letter writer to do so. The National SOP specifically states that under no circumstance should DonateLife or transplant unit staff censor or obscure part of the text in the correspondence. Correspondence should be re-written by the donor family or transplant recipient, or by DonateLife or the transplant unit with the permission of the donor family or transplant recipient.

We would urge all those that receive a letter that has been altered to inform Donor Families Australia and the OTA, via the process outlined at points 5 and 6 below.

- 3** On receipt of a letter, DonateLife and Transplant Unit staff use a date stamp to identify when the letter was received. Staff have been instructed to use the stamp on the back of the letter or the least obvious place.

The National SOP specifies that the correspondence be date stamped in a discreet location (i.e. on the back of the letter) acknowledging that while date stamping is an important part of the process,



it needs to be done discretely as staff understand the correspondence is precious and cherished by donor families and transplant recipients.

- 4 Following a recommendation by Donor Families Australia, the Correspondence Guidelines pamphlet for Donor Families and Transplant Recipients have both been updated to include a reference that DonateLife and Transplant Unit staff make copies of each letter exchanged and retain on respective files. This section of the pamphlet also outlines the process for sending correspondence and now includes a reference at the end of the section that when sending correspondence to DonateLife or the Transplant Unit, people are consenting to the process outlined. This means you will be giving consent for the DonateLife or Transplant Unit staff to open, copy and file your letter.

It is important to note that the consent to amend any text in the letter is a separate process as above at section 2.

- 5 The DonateLife webpage about contact between donor families and transplant recipients - <https://donatelife.gov.au/resources/donor-families/contact-between-donor-families-and-recipients> has been updated with information about how you can seek an update on the status of your letter and what to do if you have concerns about how your letter is being handled.

If you wish to find out the status of your letter, please contact your local DonateLife Agency. The contact details of each DonateLife Agency can be found via the **DonateLife Agency** link on this webpage (as per screenshot from the website below).

Donor families can enquire about the status of their correspondence by contacting their local **DonateLife Agency** for assistance. Transplant recipients can also contact their relevant Transplant Coordinator/Unit if they would like to follow up on the status of their correspondence.

If you have a concern about how your letter has been handled you can let the Organ and Tissue Authority know by going to the **enquiries page** link and selecting 'Donor family and recipient correspondence' from the topic drop down box (as per screenshots from the website below).

If a donor family or transplant recipient are not satisfied with the way their letters have been managed, they can notify the Organ and Tissue Authority via the form on the **enquiries page** by selecting the 'Donor family & recipient correspondence' from the topic drop down box. Awareness of these matters will help us continually improve the correspondence process and address any specific issues.



Topic * ?

Your name * ?

Your email address * ?

Postcode * ?

Phone number * ?

Your enquiry, feedback or complaint *

After you've submitted your concerns, you will receive email confirmation from the Organ and Tissue Authority to acknowledge receipt.

- 6 The Organ and Tissue Authority and Donor Families Australia have agreed to review the above feedback process every 6 months, where de-identified details of concerns will be shared to ensure awareness of these matters will continually improve the correspondence process and address any specific issues.

If you have any concerns about the correspondence process or specific feedback, please let the Organ and Tissue Authority know via the process outlined above, and/or Donor Families Australia, via the link below: <https://www.donorfamiliesaustralia.org/contact>

(Scroll down the page and enter information at General contact.)

Your feedback on an ongoing basis ensures that the correspondence system is meeting the needs of the organ and tissue donation community.

The Organ and Tissue Authority and Donor Families Australia will continue our collaboration and work together to best understand and support the needs of donor families.