

Saying Thank You

To Deceased Donor Families and Living Donors

Laura Stamp and Lisa Burnapp



Yes I donate
ORGAN DONATION

Families of Deceased Donors

Liz and Jess's story (5 min video)

In this video, transplant recipient Jess and donor family mum Liz explore the power of words. Jess's life was saved by a family like Liz's agreeing to organ donation.

<https://youtu.be/xCisLYVuiJw>

Why write?



Writing to your donor family, or a recipient of your loved one's donation is often very much ***appreciated***



Increases the ***quality*** of the donation experience, hence spreading the word of a ***positive experience***, and influencing further people to donate



We understand that writing your letter, card or email can be a very ***emotional and challenging*** experience and we're here to support you.

Key points

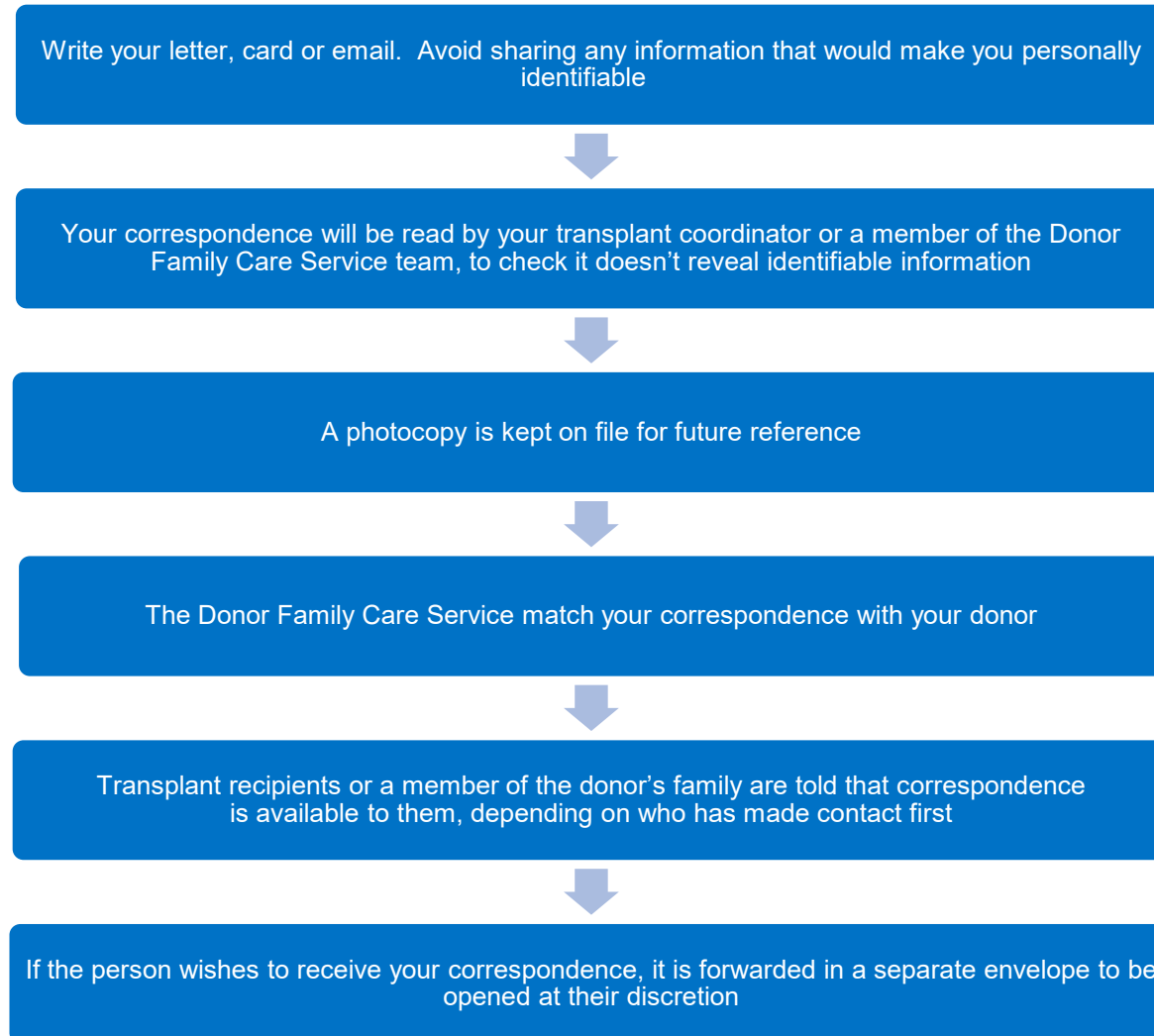
Donor families or transplant recipients can make the first contact

You can write a letter, card or email, and send photographs

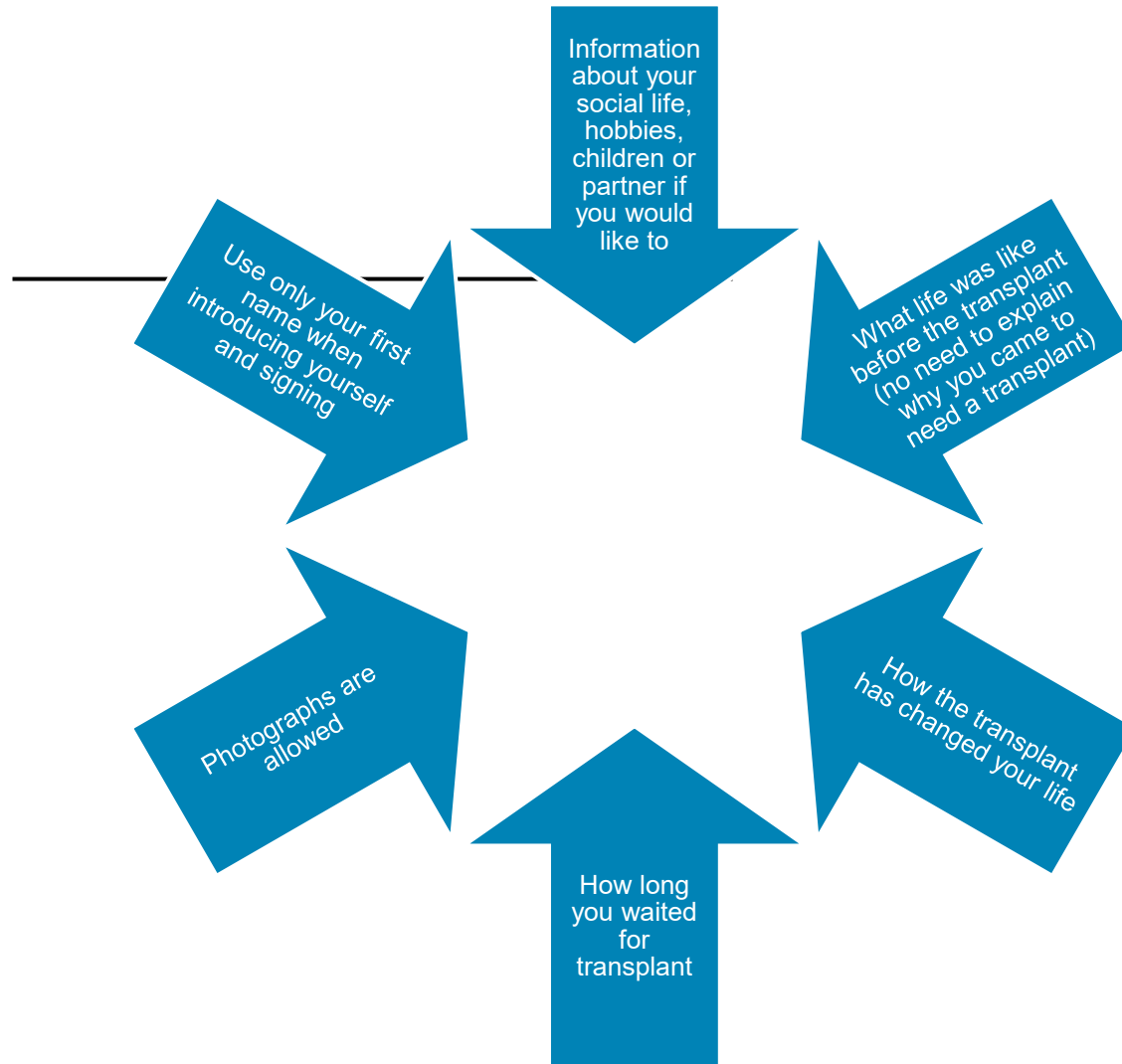
Correspondence can go to your transplant centre, or the Donor Family Care Service team via post or email

It's never too early or too late to write

What is the process?



What to write



Leaflet

“Writing to your donor family” leaflet - detailing the process of how recipients can correspond with donor families. To order hard copies please email leaflets@nhsbt.nhs.uk quoting the reference OLC number on the back of the leaflet when ordering

- <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/25265/inf1407.pdf>

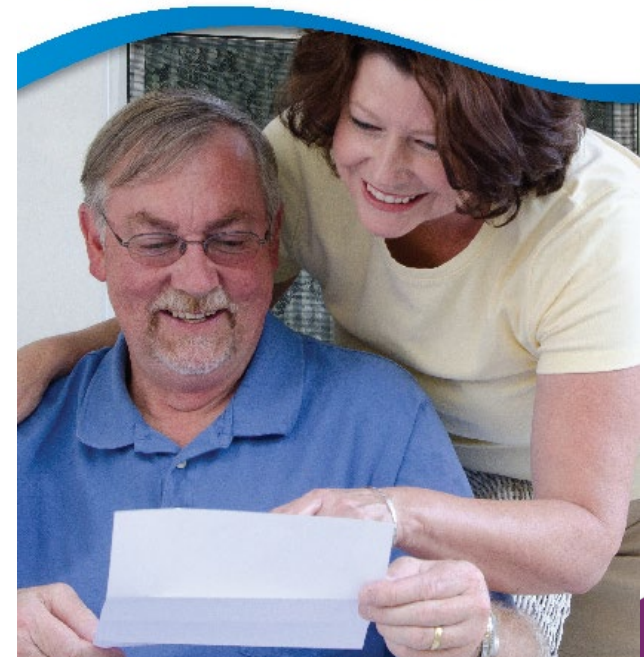


Blood and Transplant



Blood and Transplant

Writing to your donor family to say thank you





Social Media

- Be sensitive to donor family
- Never share any donor details
- Don't share dates/times or locations of tx on social media
- Recipients may open themselves up to unwanted contact from donor family or media
- Focus needs to be on recovering from the transplant, not on updating others
- Allow some time to pass before sharing the story
- Paediatrics – donors are rare



A healthcare professional in blue scrubs is holding a patient's hand. The professional's stethoscope is visible around their neck. The patient's hand has white nail polish. The background is a soft-focus clinical setting.

For professionals

- Pre transplant
 - Introduce concept of saying thank you, discuss social media guidance
- Peri transplant
 - Re-iterate social media guidance
- Post transplant
 - Explanation of correspondence process prior to discharge, provide leaflet, donor details (if requested), examples of wording
- Follow up
 - Donor Family Care Service



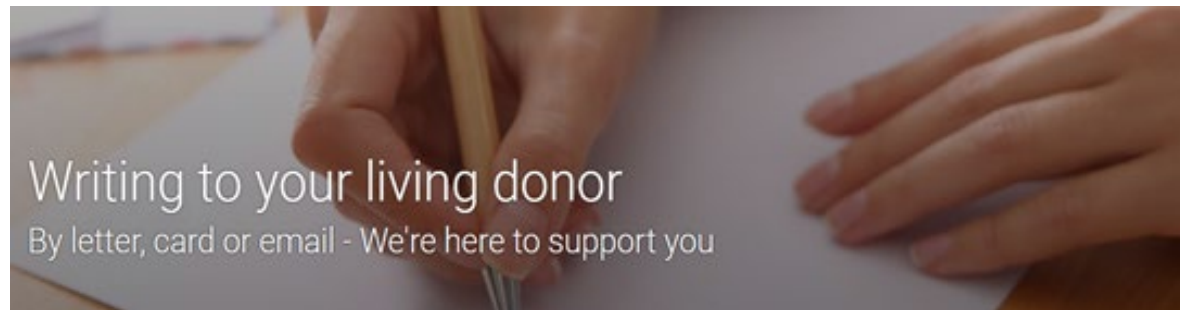
Meeting in person

- No official guidance but working group looking at the need
- Small groups
- Bring support
- One off, not ongoing relationship
- Can opt out any time
- Location mutually agreeable
- Consider virtual



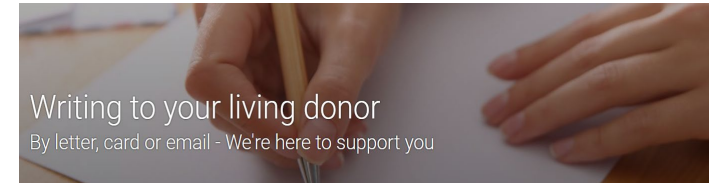
Writing to Living Donors

Lisa Burnapp



Background

- Discussion at a 'Give a Kidney' charity AGM
 - Challenging for recipients to know what to write
- Confusion over where to send correspondence due to previous deceased donation initiative
 - Misdirected to NHSBT Donor Records dept. (Donor Family Care)
- Limited information & resources available to support communication between donors and recipients of living donor transplants
- Some resources available/developed for clinical teams to write to donors
 - Template letter for centres to adapt to local requirements
 - Sheffield - 'Daisy Chain' Cards



Writing to your living donor
By letter, card or email - We're here to support you

Why?

Key points

- Communication is not expected, but is appreciated by living donors
- We understand that there are many reasons why some transplant recipients feel unable to write
- Your donor will be able to choose when to open your correspondence, at a time that is right for them
- It's never too early or late to write

www.nhsbt.nhs.uk/writing-to-your-living-donor

Original Working Group

- Lisa Burnapp Chair
- Jen Hobbs Marketing and Campaigns, NHSBT
- Helen Dobson LDC, Newcastle
- Caroline Basarab-Horwath LDC, Sheffield
- Jen Lumsdaine LDC and Living Donation Scotland
- Jan Shorrocks Executive Officer, Give a Kidney charity
- Celia Kent Living Donor
- Ewen MacLaren Transplant Recipient and Advocacy Officer, Kidney Care UK



Target audience

➤ Recipients of anonymous living donor transplants

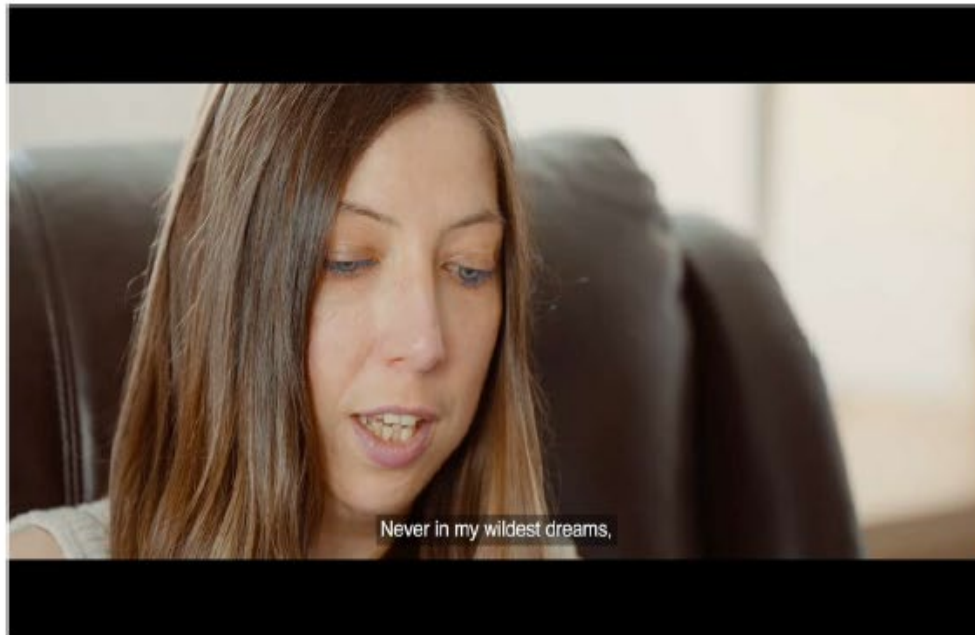
- From non-directed altruistic living donors
- Through the UK Living Kidney Sharing Scheme (UKLKSS)

➤ Multi-professional transplant teams

- Write to a living donor on behalf of the team
- Writing to an unsuitable/non-proceeding living donor
- Confirm lines of communication: all correspondence via LDCs

Resources

New webpage at: www.nhsbt.nhs.uk/writing-to-your-living-donor



Email signature and screensaver for use internal and external



Flyers to be included in discharge packs for non-directed living donor recipients

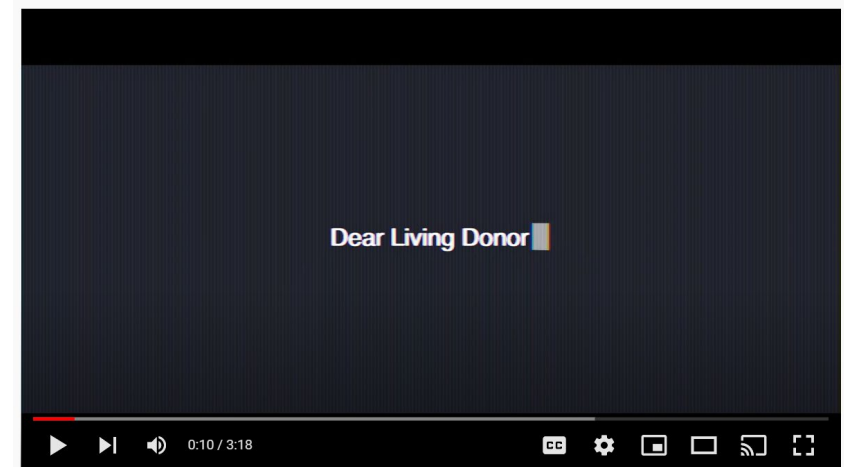
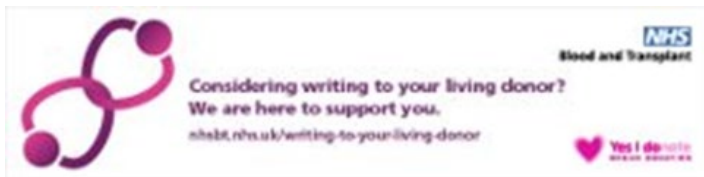


4x daisy chain cards for coordinators to send to living donors depending on the relationship to the recipient

All printed materials available to re-order, email leaflets@nhsbt.nhs.uk

Resources*

- Why write?
- What to write
- What is the process?
- Where to send your correspondence



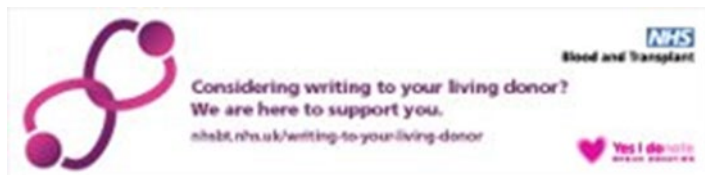
Promotional film:

www.youtube.com/watch?v=tZzCwUEYDaI

* www.nhsbt.nhs.uk/writing-to-your-living-donor

Access On-line Resources

- Watch the film
 - www.youtube.com/watch?v=tZzCwUEYDaI
 - www.nhsbt.nhs.uk/writing-to-your-living-donor
- Order printed materials (cards and leaflets)
 - www.odt.nhs.uk/living-donation/tools-and-resources/
 - Email: leaflets@nhsbt.nhs.uk



Monitoring and Evaluation

We need your help:

- Use the resources available and re-order cards and flyers when they run out by emailing leaflets@nhsbt.nhs.uk
- Make recipients aware of the initiative and guide them to the website for further information
- Keep a record of how many pieces of correspondence you are asked to pass on
 - Keep a smile box 😊
- Provide feedback
 - Via a short quarterly survey monkey about the above
 - By email to, lisa.Burnapp@nhsbt.nhs.uk

Next Steps

Following initial survey feedback

- Extended membership of WG to
 - Review/amend/extend existing living kidney resources
 - Review timing of recipient approach
 - Embed in RC/LDC education
 - Develop resources for living liver donors
 - Resurvey December 2022



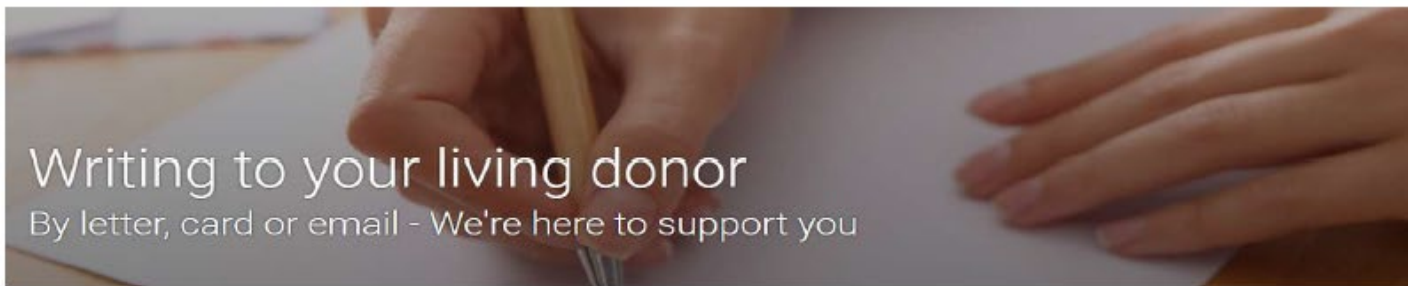
Thank You.



Writing to a donor family or recipient

By letter, card or email - We're here to support you

<https://www.nhsbt.nhs.uk/writing-to-a-donor-family-or-recipient/>



Writing to your living donor

By letter, card or email - We're here to support you

<https://www.nhsbt.nhs.uk/writing-to-your-living-donor>