

INF1598/1 – Transplant recipients and patients awaiting transplant - guidance for sharing your story



Blood and Transplant

Copy No:

Effective date: 09/12/2021

NHS Blood and Transplant oversees organ donation in the UK and raises awareness of the difference organ donation makes, saving and improving lives and providing comfort to donor families.

Those who are waiting for or who have received a transplant sharing their personal stories, raises awareness of the importance of this amazing gift - we want to inspire and to give hope.

This guidance is designed to help you, should you wish to share your experience; particularly in the media and via social media channels (like Facebook or Twitter) and is designed to help look after the wellbeing of you and those involved in your story.

Please look after yourselves and be sensitive to the donor family

We know that waiting for an organ transplant is a difficult time and your wellbeing is paramount. There is no pressure to share your journey, many patients do not and that's OK. Please prioritise your wellbeing and don't try to do too much, especially on social media.

We understand that you will experience relief and gratitude after receiving your transplant and you may want to share your story. However, it is important that you do not share the specific date or time of your transplant or any details about your donor (if you know any) with media or on social media channels. It is so easy nowadays for people to piece together information, that specific details need to be confidential for the wellbeing of both yourself and the donor family.

If you were to share such information, things may happen that you do not want or that you are not ready for. The donor family could identify themselves as part of your story and they will be recently bereaved. They are grieving and may not be ready for unexpectedly receiving more information. They may also try to contact you directly when you both are not ready and there is no support in place.

There are processes to share information between all parties and to make contact, if this is wanted, and we ask that you use these channels in the first instance should you wish to initiate contact with your donor family.

www.nhsbt.nhs.uk/organ-transplantation/resources/writing-to-a-donor-family-or-recipient/

What we advise

We recommend being quite careful about how much you update social media whilst you are waiting. Don't feel pressured to make regular updates as this can become overwhelming and when the call comes, it increases the pressure on you to update people about your transplant when you need to look after yourself. There will also be a family that has just been bereaved.

We also recommend letting some time pass between your transplant and sharing your story. Please only share your story when it feels right for you. We understand the mixed feelings you can go through and that physically it takes time to recover from your transplant. Time will also allow the donor family to begin the grieving process. We do appreciate that a gap is not always possible; the news and social media can take over and things can move both quickly and unexpectedly. We're always here to advise and support you if this happens.

We advise being as vague as possible on the date and time of your transplant, only giving the month and year e.g., April 2015. If the transplant was of more than one organ or the donor was a child, please seek further advice from your transplant unit. Please do not share any details about your donor.

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Some people want to share their story on social media/websites and can find it helps them. We recommend setting up private groups/posts/links as anyone can search for and find your details on public pages, including the media who can freely use these details as they are in the public domain.

Support is available

NHSBT wants everyone to have a positive experience of organ donation and transplantation. Please contact your transplant co-ordinator if you need any further advice around sharing your story.

NHS Blood and Transplant press office can be contacted on 01923 367600 and pressoffice@nhsbt.nhs.uk