
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.

By child donor families sharing their personal stories, awareness can be raised 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 child's experience; particularly in the media and via social media channels (like Facebook or Twitter) and is designed to help look after the wellbeing of your child, your family and those involved in your story.

Please look after yourselves and be sensitive to the recipients

We understand that there are intense feelings and emotions experienced after donating your child's organs; there is grief and pain but also pride and comfort. It is normal to want to share this, however it is important that you do not share the specific date or time of donation or any details about the recipient/s (if you know any) with media or on social media channels. It is easy for people to piece together information and specific details need to be confidential for the wellbeing of your child, your family, and the recipient/s.

If you were to share such information, things may happen that you do not want or that you are not ready for. The recipients may try to contact you when you both are not ready and there is no support in place.

Also, they may not be ready for this information and may still be recovering or facing complications. 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 child's recipient/s.

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

What we advise

We recommend letting some time pass between your child's donation and the sharing of their story. Please only share their story when it feels right for you. This will allow you the time you need to grieve properly. 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. There is support available, please contact us if there is media/social media interest in your child's story.

We advise being as vague as possible on the date of your child's donation in the media where possible, only giving the season and year, e.g., spring 2015. If the donation was something rare, e.g., more than one organ was donated to the same person, please seek further advice from the Donor Family Care Service (see below).

Some people want to share their child's 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.

We are here to support you

NHSBT wants everyone to have a positive experience of organ donation and transplantation and we are here to support donor families. Please contact the Donor Family Care Service on 0151 268 7250 or donor.familycare@nhsbt.nhs.uk if you need any further advice around sharing your child's story.

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