

# INF1600/1 – Child transplant recipients and children awaiting transplant - guidance for sharing your child's story



Blood and Transplant  
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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.

Families sharing the fact their child is waiting for or has received a transplant, 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 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 donor family**

We know that having a child waiting for an organ transplant is a difficult time. Your child and your family's wellbeing are therefore paramount and there is no pressure to share your child's journey, many parents do not and that is OK. Don't try to do too much, especially on social media.

We understand that you will experience both relief and gratitude after your child has received their transplant and you may want to share their story. It is important though that you do not share the specific date or time of the transplant or any details about your child's donor (if you know any) with media or on social media channels.

Donations and transplants involving children are rare, being careful about sharing specific details is very important. 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 donor family.

If you were to share such information, things may happen that your child and your family do not want or 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 more information at this stage in such an unexpected manner. They may also try to contact your family or your child when none of you are ready for this and there is no support in place.

There are processes in place 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 donor family.

[www.nhsbt.nhs.uk/organ-transplantation/resources/writing-to-a-donor-family-or-recipient/](http://www.nhsbt.nhs.uk/organ-transplantation/resources/writing-to-a-donor-family-or-recipient/)

## **What we advise**

Being careful about how much you update social media whilst your child is waiting is important. Don't feel pressured to make regular updates as this can become overwhelming and when the call comes, it increases the expectation on you to update people about your child's transplant when you need to look after them and yourself. Also bear in mind how your child will feel about the update and the details involved. They may be uncomfortable with their transplant journey being shared with others later in life.

We recommend letting some time pass, between your child's transplant and the sharing of their story. Please only share their story when it feels right for you and most importantly, for them. We understand that there will be mixed feelings and that physically it will take time for your child to recover from their 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

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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 and time of your child's transplant in the media, only giving the season and year e.g., spring 2015. If the donation was something rare, e.g., more than one organ was transplanted, please seek further advice from your transplant unit.

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. Please do not use specific dates or any donor details.

## 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 child's story. NHS Blood and Transplant press office can be contacted on 01923 367600 and [pressoffice@nhsbt.nhs.uk](mailto:pressoffice@nhsbt.nhs.uk)