## INF1601/1 – Donor families - guidance for sharing your story

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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.

By 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 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 recipients

We understand that there are intense feelings and emotions experienced after donating your loved one'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 so easy nowadays for people to piece together information, that specific details need to be confidential for the wellbeing of both yourself 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 directly 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 the 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 loved one donating and sharing of your story. Please only share your 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. We're always here to advise and support you if this happens.

We advise being as vague as possible on the date of donation where you can, only giving the month and year, e.g., April 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 story on social media/websites and can find that this 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 you. Please contact the Donor Family Care Service on 0151 268 7250 or <a href="mailto:donor.familycare@nhsbt.nhs.uk">donor.familycare@nhsbt.nhs.uk</a> if you need any further advice around sharing your story.