

**Paediatric
and Neonatal
Tissue Donation.**

**Information for
Health Care
Professionals**





Paediatric and Neonatal Tissue Donation

Many families who have a child with a life-limiting illness or a child admitted with an acute condition where the child is not going to survive may wish to consider tissue donation. Discussing an Anticipatory Care Plan may also lead families to ask whether donation is an end of life option for their child. It is therefore important that a discussion takes place with the specialist staff responsible for tissue donation in Scotland.

Referral

If there is potential for the child or baby to donate tissue, early contact should be made with the Tissue Donor Coordinator at the Scottish National Blood Transfusion Service (SNBTS). The contact details are:

07623 513987 (24/7 on call radio page)

The referral of each paediatric tissue donation will be assessed on an individual basis. The age and weight of the donor will be taken into consideration to ensure that the potential for donation is appropriate. The donation of hearts from paediatric donors is possible from 36 weeks corrected gestational age and eye donation from 3 years of age.

Early referral ensures the appropriate information on any donation potential is discussed with an expert and an initial assessment is made on whether donation is possible. It also allows for planning around any discussion with parents and family.

Legislation

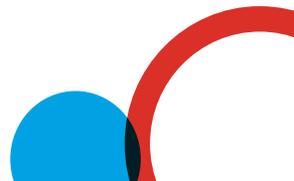
Under the Human Tissue (Scotland) Act 2006, Authorisation from the person(s) with parental rights and responsibilities (PRR) for children under 12 years, must be obtained for donation to progress. Children over 12 years who register on the ODR are deemed to have lawfully given Authorisation to donation under Scottish Law and additional Authorisation is not legally required, however discussion with the family will always take place

The Tissue Donor Coordinator (TDC) will usually speak to the family about donation by telephone, rather than face to face. If the family wish to speak in person and there is a TDC available, the TDC will do their best to attend. This conversation takes about 20 minutes.

Medical and Social History

In order to ensure the safety of organs and tissue for transplant, the TDC will need to ask some questions about the child's medical and lifestyle history. Some of the questions are of a sensitive and personal nature. They are similar questions to those asked when someone donates blood. With regard to babies and small children, we would also need to take this history from the mother, especially if the child has been breast fed in the last 12 months or is under the age of 18 months.

Assessment will be required along with the taking and testing of relevant blood samples from the child and/or the mother for serious infection and blood borne viruses. This conversation takes about 20 minutes as well.





Practical and logistical considerations

In order for donation to proceed, many practical and logistical considerations must be met. These include:

- The death has to be confirmed by a doctor.
- Blood samples for testing must be taken to ensure safety of the tissue. These must be within 7 days of death.
- The body must be cooled within 6 hours of death – currently this means in a designated mortuary but we are working towards including fleximort/cuddle cots and each case will be assessed on an individual basis. Many families find it difficult to let their child be moved to a mortuary so soon after death.
- The place of death e.g. hospital/hospice or home may have a bearing on the ability to transfer to a mortuary.
- There are retrieval specialists available to retrieve the tissue within 24 to 48 hours of death.
- Most retrievals for heart valve donation in children will be carried out in either Glasgow or Edinburgh by a paediatric pathologist.
- If the death has been referred to the Procurator Fiscal (PF) for any reason, then explicit consent from the PF is required before donation is possible.

Retrieval

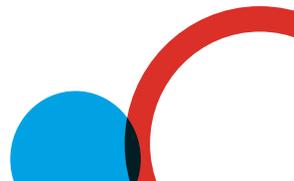
Tissues need to be retrieved within a set timeframe after death; eyes within 24 hours and heart valves within 48 hours. The retrieval procedure is undertaken at designated hospitals in Edinburgh and Glasgow by specially trained staff. The procedure itself can take several hours as we take as much care retrieving tissue/organs as we do when transplanting it in the recipient. Once the retrieval is complete the child will be returned to the hospital / funeral director / family.

Why is Tissue Donation so Important?

A tissue transplant greatly enhances the quality of people's lives - and can even save lives.

Donation of tissues, especially in cases where organ donation is not possible, can offer the opportunity for families to fulfil their loved one's wishes.

Many bereaved families take comfort in the knowledge that their loved one has helped others.



Alex



Before he was born, Alex was diagnosed with a rare form of heart disease. This meant he required life-saving surgery and at two weeks old, he needed his first operation. Alex was given a donated heart valve but unfortunately it later failed. At 18 months of age he faced further surgery to receive a replacement valve.

Alex's mum, Julie, said:

“After his first operation he did remarkably well, but there were complications which left him with difficulties. He then required a further valve replacement and is doing fab now. His heart is doing great and looking at him you wouldn't even know anything was wrong.”

“It's very humbling, somebody else lost their child and enabled me to keep mine. It's been twice in our case and it's made a huge difference, my little boy is running around enjoying life.”

Alex is now a happy child, although he is likely to need more procedures throughout his life.



Contact us

Tissue Donor Coordinator – 07623 513987
(24/7 on call radio page)

Scottish National Blood Transfusion Service
Tissues, Cells & Advanced Therapeutics
The Jack Copland Centre
52 Research Avenue North
Edinburgh, EH14 4BE

To help others after your death, make your wishes known by telling your family or next of kin and join the Organ Donor Register by calling: **0300 123 23 23**
or visit [organdonationscotland.org](https://www.organdonationscotland.org)

This publication can also be made available in large print, braille (English only), audio tape and in different languages.

If you would like further information contact
nss.communications@nhs.scot

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