

**NEONATAL HEART VALVE
DONATION GUIDELINES AND
PROCEDURES**

NEONATAL HEART VALVE DONATION GUIDELINES & PROCEDURES

See also: Guidelines to Follow in the Event of a Death on NICU

This policy and procedures are based on the guidelines for “The Process for Tissue Donation” as produced by Tissue Services. To make a referral or for advice Tissue Services can be contacted via their pager at any time on 0800 432 0559.

POLICY

1. The opportunities for this to be offered to bereaved parents will be few and it is acknowledged that it is a very difficult time, not only for the family but also for the staff caring for them. Heart valve donation however, can be seen as a positive event following the tragedy of their baby’s death and therefore should be offered to them if deemed appropriate in their circumstances and if the deceased baby meets the criteria for donation.
2. Apart from heart valves, at present there are no other neonatal organs or tissues suitable for donation. Valves are precious and rare and used in transplantation to correct congenital heart defects and there is a very high success rate with no problems of rejection. The usual course is that the valve starts to fail when the child has outgrown the valve but failure is slow and monitored with a replacement valve being a planned procedure.
3. The neonatal staff are responsible for assessing eligibility, initially approaching parents and supporting them as they consider the options available to them. The Tissue Services (TS) then deals with service availability, parental consent and transport arrangements.

ELIGIBILITY

- Weight over 2.72kgs
- No maternal history of HIV, CJD, auto-immune disease, disease of unknown aetiology, significant systemic uncontrolled infection – although these can be discussed with the tissue coordinator
- Parental consent must be obtained

Contraindications

- HIV, Hep B/C
- Suspected CJD
- Mother/Father high risk behaviour
- Active TB
- Cancer – myocardial tumours
- Valve defects
- Rheumatic fever

If you have any queries about donor suitability or would like further details, please contact TS 0800 432 0559.

PROCEDURES (See Appendix 1 for flow chart)

1. Heart valve donation should be discussed with the parents by either a nurse or doctor familiar with the process. In order to prevent parents being further distressed always check eligibility and service availability prior to approaching family. If appropriate and baby is eligible, around the time of death or imminent withdrawal of intensive care, a senior nurse/doctor should inform the family of the option for neonatal heart valve donation. If the parents then wish to have further information then the information sheet (Appendix 1) should be given to parents at this time and Tissue Services should be contacted on 0800 432 0559.

The decision to donate must be clearly established in one of the following ways:

- A positive response by the parents to the suggestion of donation made to them by a health care professional
- A spontaneous offer of donation made by the parent/next of kin

This must be clearly documented in the baby's medical notes.

2. Heart valve donation should only be offered if the baby meets the inclusion criteria (see above) and there are no contraindications. Parents are unlikely to agree to this if post mortem has been declined but it is important to inform the parents that valves can also be removed when post mortem is not required or wanted.

If for any reason donation is not possible, this must be clearly and sensitively explained to the parents and the discussion documented in the baby's notes.

3. Once parents have agreed or offered to donate, a referral should be made to Tissue Services (TS). One phone call will trigger the process and the Tissue Donor Co-ordinator (TDC) will make all arrangements for donation. They must be contacted IMMEDIATELY by pager on 0800 432 0559.

This pager number is answered between 08.00 and 20.45 by the Tissue Services Co-ordinators 7 days a week. They will take the referral and let you know if the baby is suitable. If the parents want to donate they will take consent and arrange for the retrieval to happen. Outside the above hours the pager number is the same but it goes through to Organ Donation and Transplantation (ODT) duty office. They will answer the page and take minimal information and advise that the tissue services coordinator will call them back within office hours to discuss suitability.

You will need to state the name of person making the call, contact telephone number and that it is with reference to the possible donation of neonatal heart valves.

Information required

- Baby's name and date of birth
- Date, time and cause of death (if known)
- Past medical history of mother and pregnancy
- Where the baby died and where he/she is now
- Name, address and telephone number of the next of kin
- Name and contact number of mother's GP
- Is there to be a post mortem? If so, is there a planned date/time for it to proceed?

If the baby's death is to be referred to the Coroner, the Coroner's Officer MUST be contacted via switchboard to obtain permission for donation. If the Coroner's Officer is unable to give permission for donation this must be clearly and sensitively explained to the deceased patient's family and the discussion documented.

4. The TDC will contact the family by telephone to obtain consent before donation can proceed. The format of such calls is legally and ethically approved and will be recorded on a CD. Written consent is not necessary for tissue donation providing parents give their verbal consent and this is recorded. The TDC will explain what is involved, take a detailed medical history from the mother (similar to those asked prior to blood donation) and will gain consent. They will also give the opportunity to ask any additional questions about the donation.

5. Information for Parents

Although the TDC will telephone the parents and explain exactly what is involved in neonatal heart valve donation, they may however have questions prior to this and the following information may be useful:

The whole heart will be removed. The heart will not be returned to the body and excess tissue will be disposed of by cremation. Heart valves remain in quarantine for 6 months and can be stored for up to 10 years, although this is unlikely. Feedback is available if requested, but this is currently limited to knowledge of the sex and age of the recipient.

6. Care of the baby and parents

This is a time requiring particular sensitivity, in that the parents must be able to spend as much time as they wish with their baby to say goodbye. Retrieval must be completed within 48 hours and for the valves to be retrieved in good condition staff should aim to place the baby in the mortuary fridge within 6 hours of death. This must be explained to the parents when it is clear that heart valve retrieval is likely to proceed so that they don't feel rushed at this important time. If this is not achieved, the donation may need to be performed within 12 hours of death. This would have to be communicated to the heart valve bank as soon as possible otherwise the retrieval team may not be able to arrange this in time.

Parents may spend time with their baby again for short periods of time, but TS would need to be aware of the timings so a judgement could be made on a case by case basis.

7. The Bereavement Office must be informed by telephone if donation is to go ahead. Also ensure the mortuary are aware by writing clearly on the mortuary admission form that baby is for heart valve donation. If baby is to have a post mortem the Bereavement Office will arrange transport and the transplant team will liaise directly with them so that the retrieval will take place at St Georges Hospital at the same time. If there is not going to be a post mortem then retrieval will take place in the St Peters Hospital Mortuary.
8. While waiting for this to be organised the actions usually performed for bereaved parents can be carried out as per the Guidelines to Follow in the Event of a Death Occurring on NICU.

In addition 6mls of blood will need to be taken from both mother and baby in clotted sample (red top) tubes. This blood can be taken up to one week prior to, or 24 hours after, baby's death. This should accompany baby to the mortuary. Mum will need to provide a further blood sample in 6 months time to test for viral infection e.g. HIV.

9. The parents should be given the written information leaflet (appendix 2) any further help or advice that they may need. They should also be given the telephone number of the NICU in case they later need any further clarification or support.
10. All action taken by the health care professional concerned must be clearly documented by them in the baby's medical notes.

Contact Numbers

Tissue Donor Coordinator (National Blood Service)
Specialist Nurse Organ Donation

0800 432 0559
pager 07659 590529

References

Human Tissue Act (2004) Code of Practice for the donation of Organs, tissues and cells for transplantation. www.hta.gov.uk

Kaye, J. (2004) A Guide to the Human Tissue Act www.ethics-network.org.uk

Kirkpatrick, M. and Martin, T.(2009) Heart Valve Donation Following Perinatal Death – MAT/Postnatal/21. Buckinghamshire Hospitals NHS Trust.

NICE (2011) Organ donation for transplantation: Improving donor identification and consent rates for deceased organ donation. Draft for Consultation.

Shafer, T.J.(2009) Improving relatives' consent to organ donation. BMJ, 338:b701.

Sque, M., Long, T. and Payne, S.(2003) Organ and Tissue donation: exploring the needs of families. Executive Summary

Watts, C. (2009) Editorial: Neonatal Heart Valve Donation. Journal of Neonatal Nursing, 15, 74 – 76

Compiled by:	Sister Lynn Parker, Neonatal Intensive Care Unit
In Consultation with:	NHS Blood and Transplant Services and Jessica Gregory
Ratified by:	ASPH Organ Donation Committee and NICU Clinical Management Group
Date:	Original Compiled 7 th August 2012 Updated 30 th October 2014 by Dr Otunla, Neonatal Consultant
Date for Review:	October 2017
Reviewed by:	Annie Mann, Deputy Sister NICU. Consulted with NHS Blood and Transplant Services – no additions/alterations required.
Date of Review:	November 2018
Date of next review:	November 2022

Appendix 1

THE PROCESS FOR HEART VALVE DONATION

CHECK ELIGIBILITY TO DONATE & Confirm service availability

Tissue Services 0800 432 0559 (Have medical notes ready)

ONLY IF PATIENT SUITABLE & Service is available

OFFER DONATION TO THE PARENTS

(If interested in donation obtain contact number and time for family interview)

INFORM TISSUE SERVICES

DONATION TO PROCEED

AFTER DEATH

CONTACT TDC

Give the following information

About baby: Their name, date of birth, date, time and cause of death, details of past medical history and any medications taken, name, telephone number and address of the GP

About mother: Their name, address with a telephone number where they can be easily contacted. The relative should be informed that the Tissue Donor Co-ordinator would need to speak to them before the donation can proceed. They will be asked some questions about past medical history and high-risk activities.

INFORM BEREAVEMENT OFFICE AND MORTUARY

If baby for post mortem – obtain consent. They will arrange transport of baby to SGH and retrieval team will liaise with them

USUAL AFTERCARE

As per Guidelines to Follow Following Death on NICU

CONSENT

TDC will phone and obtain mum’s consent and ask questions about past medical history

Remember the Tissue Donor Co-ordinator is always available for advice at any time during this process