

Organ Donation and Babies with an Antenatal Diagnosis of a Life-Limiting Condition

Introduction

There are a small but increasing number of enquiries from clinicians and parents about the possibility of organ donation from small infants who have been diagnosed antenatally with anencephaly and other life-limiting conditions.

NHS Blood and Transplant wishes to be supportive of the parent's wishes for their baby to be an organ donor. However, it is also necessary to be realistic in managing expectations.

Therefore, parents and referring clinicians should be aware that, at present,

1. Hepatocytes may be prepared from donated liver and used for transplantation.
2. Heart valves may be retrieved if the baby weighs more than 2.5kg.
3. More often than not, donation will not be possible, for the following reasons:
 - Mode of delivery: to proceed with hepatocyte donation there should be an agreed planned elective Caesarean Section irrespective of any discussions regarding organ donation. Heart valve only donation may be possible at the time of death irrespective of the delivery mode.
 - The baby may be stillborn.
 - As with other forms of DCD donation, the time interval between treatment withdrawal (which is considered to be the point of delivery and placental separation) and asystole may be prolonged.

Responding to the enquiry or referral

Each case must be discussed with the Team Manager, Regional Manager and Lead Nurse: Paediatric and Neonatal Donation and Transplantation to define a clear plan of action, ideally prior to any family discussion and prior to any exploration around organ suitability with recipient centres. The decision regarding proceeding to further planning of the process must be made in conjunction with the Regional Manager.

Liaison with the Associate Medical Director (or in their absence the National Clinical Lead for Organ Donation) may be required following the planning meeting and any outstanding items clarified. Subsequent planning meetings will be identified throughout the process as required.

Possibility of transplantation

Kings College Hospital, London may accept hepatocytes for their transplant programme. Following the initial planning calls [FRM5510](#) Neonatal and Infant Donor Assessment and Organ Screening should be used for assessment.

Heart valve donation may be possible should specific criteria be met.

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Donor hospital multi-disciplinary team

If donation is a possibility, a local hospital team should be established to ensure that the necessary arrangements and safeguards are in place to support the process further.

The team should include:

- SNOD Lead - Donation after Antenatal Diagnosis for the region
- Hospital CLOD and SNOD
- Appropriate clinical specialities as appropriate – obstetrics, midwifery, foetal medicine, neonatology and palliative care.
- It may be appropriate to inform the hospital governance (such as Head of Nursing, member of the hospital clinical ethics committee).

The role of the team is to:

- Define and implement a pathway for donation which is acceptable locally and consistent with national guidance.
- Ensure that consent/authorisation for donation is fully informed and obtained in a timely fashion.
- Liaise with the retrieval and implanting teams and ensure that as much information as possible is available to guide donor assessment.

Consent / authorisation

It is vital that parents understand that the likelihood of donation taking place is low and that it may only be possible to use hepatocytes for transplantation.

Organ assessment

The following information should be made available to the retrieval surgeon

- Ante-natal ultrasound scan
- Report of foetal anomaly scan (performed at 16-20 weeks)
- Presence of any noted complications
- Estimate of foetal weight (this can be estimated by Ultrasound Scan and can be requested by the maternity team).
- Maternal U&Es

Post-donation support

Whether or not donation proceeds, families will need support as is current practice. Press attention: in some cases, parents or family members have shared their experience on social or other media. Families need to be counselled about the implications and timing of approach in the media. The Press Office should be contacted so that the family can be offered the support they may want or need.

It should be remembered that such donations can have a psychological impact on the SN-ODs and retrieval team members and appropriate support may be needed.