

## Organ and Tissue Donation in Small Infants

In the UK there are a number of small infants who are waiting for size matched organs; transplantation may be the only treatment option for them. Without families supporting organ donation, these infants may never have the opportunity of a lifesaving gift; they are likely to die on the waiting list.

Many families express that they are grateful for the opportunity to consider organ and tissue donation, and often describe a sense of pride that something meaningful has come of their baby's short life even when it is ultimately not possible.

### **Who and When?**

Heart valves (Tissue donation) can potentially occur from 32 weeks CGA (36 weeks CGA in Scotland) and solid organ donation from 37 weeks CGA.

**Solid organ donation** usually occurs in an intensive care environment where either a decision has been made to withdraw life-sustaining treatment and it is thought that death is likely to occur shortly after this withdrawal (Donation following Circulatory Death / DCD), or where death is determined using neurological criteria (Donation following Brain Stem Death / DBD).

A notification to the Specialist Nurse (SN) team should be made when End-of-life-care (EOLC) options are being considered. This enables organ and tissue donation to be incorporated in the decision making when it is a possibility. Time is required to assess and establish if donation is a potential EOLC option and therefore notifying the SN team at the earliest opportunity is important.

**Tissue donation** can potentially occur following death in any setting, but careful screening is necessary to ensure there is a requirement for the tissue. This is particularly important in small infants, where there are many elements to consider. Suitability and need can be assessed by a SN at the time of death and a clear understanding gained regarding specific considerations for retrieval of the tissue/s.

There are many elements that affect organ and tissue donation, particularly in small infants. It is important to discuss each case individually with a SN, who will be able to advise and guide clinical teams and the family through the process and explain why organ and tissue donation may or may not be possible.

### **Specialist Nurse Contact (24 hour / 7 days a week)**

Please call the SN team where a baby falls into the age criteria and you are beginning to discuss EOLC options, you consider death is likely to occur in the next 48 hours, a family asks about organ and tissue donation, or the baby appears to meet the criteria for neurological death testing.

**The UK Organ Donor Referral Line launches**



**03000 20 30 40**

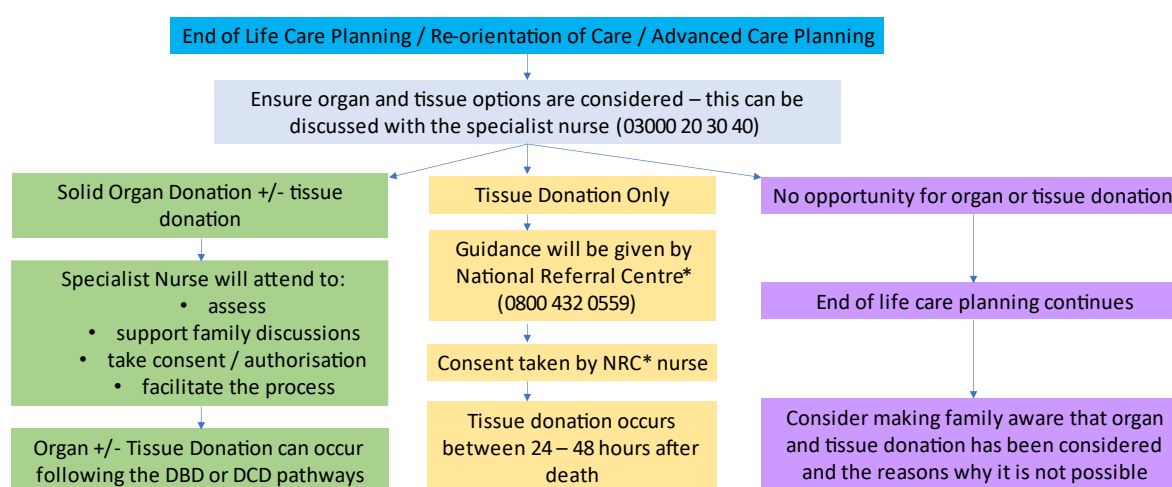
Please use this number for all organ donor referrals.

# Guidance for Neonatal Units when considering Organ and Tissue Donation as part of planning Palliative and End-of-life-Care



The SN will assess suitability in discussion with the clinical teams treating the baby, guidance policies and with transplantation teams where appropriate in this assessment.

They will discuss the option of donation fully with the clinical teams and will only speak to the family as part of a specifically agreed plan with the clinical and multi-disciplinary teams.



\* In Scotland guidance / support will be given by Scottish National Blood Transfusion Service (SNBTS) Tel: 07623513987

## Determination of Death by Neurological Criteria:

Determining death by neurological criteria has been possible in term infants from 37 weeks post-gestational age to two months since 2015. Please use this link to the latest RCPCH guidance document: [Diagnosis of death by neurological criteria \(DNC\) in infants less than two months old - clinical guideline | RCPCH](#)

*Additional resources can be found through the links below:*

Video links for testing training: [Diagnosing death using neurological criteria - ODT Clinical - NHS Blood and Transplant](#)

Links to RCPCH and BAPM endorsed guidance forms: [Paediatric care - ODT Clinical - NHS Blood and Transplant](#)

This pathway can lead to DBD (donation following brain death) donation. In small infants there may be more options for organ retrieval by this route i.e. heart donation and multi-organ grafts

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The SN will guide you through this process.

## **Donation Following Circulatory Death (DCD)**

Where the clinical team are considering that ongoing life sustaining treatment is futile, organ and tissue donation may be an option.

The SN is there to support clinical teams and families to ensure that where organ and tissue donation is an option it may be incorporated into the end-of-life decision making process.

There are limited options for organ donation by this pathway and despite best efforts there are occasions where organ and tissue donation may not be possible or logistically it is not able to progress.

The SN will ensure clinical teams and families are fully supported through the process.

## **What can potentially be donated?**

What that can potentially be donated is dependent on many factors, the SN can provide further guidance.

It is also important to understand that the waiting list changes daily and therefore the need will also change.

## **How often does organ donation occur in small infants?**

Between 2009-2019 there were a total of 40 infants aged <4 weeks old who became donors. Of these 14 donated both organs and tissues and a further 26 donated tissues only.

Donation and transplantation from small infants is rapidly evolving, NHSBT are working closely with clinical colleagues and the transplant teams to support further work in both establishing the potential for organ and tissue donation through audit and the transplant need.

## **Considerations when writing Palliative and EOLC policies.**

Liaise with the SN and clinical lead for organ donation (CLOD) allocated to your trust.

Consider how NICU EOLC practices can fully incorporate providing families with the opportunity to consider organ and tissue donation where it is possible.

Work alongside the SN to consider how organ and tissue donation can be facilitated in practice, this will include the following:

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- discussion regarding location and practices of WLST
- determination of death
- Advanced Care Planning discussions
- supporting families through the process (roles and responsibilities)
- supporting families and clinical teams in how donation can be incorporated into EOLC planning
- accessibility and availability of theatres for the retrieval operation
- post donation care of the baby and family
- use of cold cots / cold room / hospice care and its impact on organ and tissue donation
- If there is to be a post mortem and discussions with the perinatal pathologist

Consider debrief sessions to further support all staff following this process and subsequent donation.

## **Organ Donation where there is an antenatal diagnosis of a life-limiting condition**

Due to the rarity of these cases proceeding to organ and tissue donation we ask that it only be explored if directly raised by the family. In these cases, the SN will be happy to guide clinical teams and families through the process.

For further guidance see [sop5874.pdf \(windows.net\)](#)

## **For further information**

There is a SN and CLOD linked to each hospital. To find out how to contact yours please visit the link here. [Regional organ donation teams - ODT Clinical - NHS Blood and Transplant](#)

## **Case Studies / family stories**

Case study

Millie [Minnie Duggleby becomes 1 of Britain's youngest organ donors at 23 days old | Daily Mail Online](#)

Angelo Ray ['My newborn son - the organ donor' - BBC News](#)

*Further clinical case studies can be provided on request*

## **Additional Information / links**

For Paediatric Organ Donation Policy [sop5874.pdf \(windows.net\)](#)

For further information please go to [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)

Further clinical information [www.odt.nhs.uk](http://www.odt.nhs.uk)

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For further training more information is available [Education and training - ODT Clinical - NHS Blood and Transplant](#)

For any additional enquires please email [enquiries@nhsbt.nhs.uk](mailto:enquiries@nhsbt.nhs.uk) and mark for the attention of the Lead Nurse for Paediatric and Neonatal Donation