



## Unborn Baby with Serious Abnormalities Organ and Tissue Donation options – guidance

### ***Introduction***

There are a variety of options for organ and sometimes tissue donation from neonates and, in the context of such serious fetal anomaly that death in the neonatal period is anticipated, parents and their families can be prepared in advance. There are two types of organ donation: donation after brain death and donation after circulatory death.

In the context of fetal anomaly, it is likely that only donation after circulatory death will be considered as one of the key criteria for brain death is that the patient has to already be ventilated. It is unlikely there will be situations where babies that are known to have such serious abnormalities will be ventilated. However, following a review in November 2015 by the Royal College of Paediatrics and Child Health (RCPCH) <sup>1</sup>, brain death can now be diagnosed in neonates under two months old; this was not previously considered appropriate.

### ***Nomenclature***

Abnormality and anomaly are synonyms and, in this, the term abnormality will be used as most parents and their families will understand it more easily. There is a tendency to talk about 'lethal' anomaly, but this is hard to define<sup>2</sup>. Serious abnormality will be used in this document. In essence, we are considering abnormalities that, despite medical intervention, are likely to result in death during the neonatal period. However, very little is certain and there have been cases of babies with anencephaly living into infancy<sup>3</sup>.

### ***Imperative***

There is an ongoing need for organs and tissue in order to save lives. Even one or two more donors a year could make a significant difference. Neonatal organs are currently being transplanted into other children, neonates and even small adults. Neonatal organs may lead to fewer rejection problems than adult organs. At present, the following can potentially be donated from neonates:

- Kidneys
- Liver hepatocyte cells

- Heart valves
- Lungs (in limited circumstances)

As at 31 March 2017, there were 526 people in Scotland on the active transplant list waiting for one or more organs, with people still unfortunately dying each year before an organ becomes available for them. Therefore, while progressing donation from new born babies is challenging, it is important to do all we can to help people on the waiting list.

### ***Circulatory Failure and Brain death***

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

For organ donation to be able to proceed in this context, there has to be:

- Parents who are willing to support and authorise the donation
- Live birth after 36 weeks – normally the baby may need to be delivered by caesarean section or induced so that the timing of the donation can be planned (under 36 weeks gestation, donation would unfortunately not be an option)
- Suitable recipient(s) available
- A surgical retrieval team available to come to the unit where birth has occurred and a theatre available for that team to use
- Death to occur within a three hour timescale following delivery as, in the absence of ventilation, the organs deteriorate too much due to hypoxia to be safe to transplant
- The parents' agreement to their baby being moved to the theatre for organ retrieval within five minutes of death

This may seem an insurmountable list of issues, but successful donation can occur with due preparation and good counselling. For those cases where successful donation has occurred, parents can find comfort from the fact that their baby saved or improved the lives of others.

#### *Donation after Brain Death (DBD)*

This is unlikely to be an option in the context of fetal anomaly. However, the advantages of organ retrieval from a donor following brain death include:

- Time for preparation for the grieving family – the family have more time to spend with their baby after death.
- Practical and psychological preparation time: theatre time can be scheduled in advance, all the logistical arrangements of identifying recipients for the organs and organising the retrieval team is therefore more controlled.

Despite these apparent advantages, it must be made absolutely clear that there is no option to ventilate a neonate if this is solely for the purposes of allowing donation to occur. In addition, it has not been established that the kinds of conditions for which donation might be considered, such as anencephaly or bilateral renal agenesis, would achieve the criteria for brain stem death.

### ***Trisomies and other DNA faults***

If there were trisomy 13 or 18, it is unlikely that organ donation will be considered. If there are other chromosomal or genetic faults then donation might be an option and discussion with clinical genetics will be an important part of the process. For example, a baby that has both Turner's syndrome (X0) and acrania might be suitable for donation. For other conditions, such as DNA duplications or deletions, a judgement will have to be made as to whether this is likely to impact on the ability of the apparently intact organs to function in a recipient.

### ***Timing***

On breaking the bad news about the serious abnormality, clearly many women will choose to terminate their pregnancy. Normally donation should only be discussed with the parents either in cases where the parents themselves raise it or where the woman has decided that she wishes to proceed with her pregnancy. However, where a woman wants to consider her options and the pros and cons of continuing with her pregnancy, donation can be mentioned as an option before the decision on whether to continue has been made. Nonetheless, it should go without saying that there should be no coercion or pressure on parents to continue a pregnancy that otherwise might have been terminated simply to allow the option of organ donation. Where a woman has decided to continue with her pregnancy and an Anticipatory Care Plan or other end of life care planning is being prepared for her baby, the woman's/parents' views on whether they would like to consider organ donation should be sought.

Where parents express an interest in considering donation or where donation could be an option, you should contact a Specialist Nurse in Organ Donation (SNOD) via your hospital switchboard as early as possible. They will advise you on whether donation may be possible and arrange to come to speak to the parents. If donation is an option and the parents are willing to proceed, the SNOD will lead on making the necessary arrangements with the family, the retrieval team and, where heart valves may be donated, with Tissue Services at the Scottish National Blood Transfusion Service (SNBTS). They will work collaboratively and closely with the team caring for the pregnant woman to help ensure the family receive continuity of care, that the

necessary tests have been carried out to assess the organs and that appropriate logistical arrangements are in place to support donation.

The attached flowchart sets out the suggested order which should be followed in carrying out the key steps in the process, although this may vary depending on how the parents react e.g. whether they raise donation themselves.

### ***Procurator Fiscal***

Please note that there is no need to consult the Procurator Fiscal in these types of cases, where the baby's death is anticipated and there are no suspicious circumstances.

### ***Contact Details***

NHSBT pager (can be used out of hours) - 03000 20 30 40

SNBTS Tissue services pager (can be used out of hours) – **07623 513987**

### ***References***

1. *The diagnosis of death by neurological criteria in infants less than two months old.* RCPCH 2015 - <https://www.rcpch.ac.uk/resources/diagnosis-death-neurological-criteria-dnc-infants-less-two-months-old-clinical-guideline>
2. DJC Wilkinson, P Thiele, A Watkins, L De Crespigny - *Fatally flawed? A review and ethical analysis of lethal congenital malformations.* DOI: 10.1111/j.1471-0528.2012.03450.x <http://onlinelibrary.wiley.com/doi/10.1111/j.1471-0528.2012.03450.x/full>
3. See for example <http://www.dailymail.co.uk/news/article-3251158/Father-miracle-baby-Jaxon-just-turned-one-despite-missing-skull-opens-Internet-abuse-wife-received-letting-son-live.html>

## Flowchart

