



PAEDIATRIC AND NEONATAL ORGAN AND TISSUE DONATION

Guidance for staff in Neonatal and Paediatric Intensive Care Units and other Departments who may work with critically ill children or babies

Introduction

Why organ and tissue donation is important

Currently there are between 150-175 children in the UK waiting on a lifesaving organ transplant. This number has not decreased significantly in the last 5 years. Many of these children are waiting for organs from other children who are of a similar size. The number of paediatric donors has also remained static at between 40-60 per year across the UK, despite significant increases in adult deceased donors in the last 10 years since organ donation was reorganised following a UK-wide Organ Donation Taskforce. Many of these children waiting for a transplant will die before a suitable organ becomes available. Children's organs can also often be donated to adults on the waiting list.

While donation can be challenging, when it goes ahead, it can save and improve many lives; it can also often bring great comfort to a donor's parents and families in the years after their loved one's death to know that something positive came from the tragic death of a child. **So we need your help to make sure that no opportunities for donation are missed.**

While donation for transplantation is always the highest priority, in some cases organs and tissue are also donated for medical research, for education and training and for audit purposes. This is also very important, particularly to enable the development of treatments and other medical advances through research, which could save lives in future.

Current barriers to neonatal and paediatric donation

There are a number of reasons why it has so far been difficult to increase donation from neonatal and paediatric donors in Scotland:

- Many healthcare staff in neonatal and paediatric Intensive Care Units and other critical care areas looking after children have limited awareness of when organ and tissue donation can be considered – this guidance, along with work through NHS Boards' Organ Donation Committees, aims to help provide greater awareness, education and training for staff.

- Donation has not previously been treated as a standard care goal in end of life care planning, such as anticipatory care plans (ACPs) – it is important that organ and tissue donation should become a standard point of discussion and care planning in cases where the child’s death is not sudden.
- Due to limited awareness in some units, organ and tissue donation has not always been part of standard service delivery for neonatal and paediatric patients who are expected to die. The Scottish Government, NHS Blood and Transplant (NHSBT) and Tissues and Cells Services of the Scottish National Blood Transfusion Service (SNBTS) are keen to ensure that donation is in future seen as a recognised part of the pathway. While donation is of course sensitive, particularly when a patient’s parents and family are going through such a tragic loss, awareness of donation is increasing – including among children themselves - and it is important that patients in all units across Scotland get the same opportunities to be considered as a potential donor if that may be possible for them.

Approximate numbers of potential and actual neonatal and paediatric donors in Scotland each year

In Scotland, we have between one and five families who donate their child’s organs and/or tissue every year. However, NHSBT’s audit of deaths in paediatric and neonatal ICUs suggest there are a number of potential donors who are missed each year, particularly in neonatal ICUs, because they are not referred for consideration as a potential donor. Given the chronic shortage of many types of organs in the UK, every extra donation can make a big difference to saving people’s lives. Therefore, by ensuring every baby or child who could possibly donate their organs is considered and their families offered the choice of donation, more children and adults on the waiting list for transplant could have a chance of a significantly improved life.

What organs and tissue can be donated?

The organs which children can donate depends on the type of donation and which organs are assessed as suitable for transplant at the time of donation. Heart, lung, liver (including the liver for their hepatocyte cells) and kidneys have been donated by babies just days old and older infants and children can also sometimes donate their small bowel and pancreas.

In order to be considered as a donor, a baby needs to be over 36 weeks corrected gestational age¹. Babies from over 36 weeks gestation can also donate heart valves in Scotland and older children (of three years old or over) can donate their eyes.

¹ Corrected gestational age is the age corrected to allow for delivery prior to term e.g. a child who was born at a gestational age of 30 weeks who is now 6 weeks old would have a corrected (gestational) age of 36 weeks.

Generally, babies and children who have death diagnosed by neurological criteria (donation after brain stem death – DBD) can donate more organs than those who have death diagnosed by cardiorespiratory criteria (donation after circulatory death – DCD). Since 2015, it has been possible to diagnose death by neurological criteria in all babies at more than 37 weeks gestational age². The Academy of Medical Royal Colleges and the Royal College of Paediatric and Child Health recommend that all children who meet the preconditions for testing should have death diagnosed by neurological criteria irrespective of the potential for organ donation.

Organ donation can be taken forward at almost all hospitals in mainland Scotland, including all hospitals which have a neonatal or paediatric intensive care unit and a number of others. Even in smaller hospitals which do not have their own Specialist Nurse for Organ Donation (SNOD), a SNOD will travel to the hospital and, if a donation is likely to proceed, a team of retrieval surgeons will be sent to the hospital. Tissue donation (of heart valves and eyes) can also be taken forward at most hospitals, although in some cases heart valve donation may only be possible where the patient is also an organ donor. If you are not sure whether or not organs or tissue can be donated from your hospital, please speak to a SNOD or Tissue Donor Coordinator (TDC) about this (see contact details below).

Legal context

For babies and younger children, it is the person(s) with parental right and responsibilities for them who can authorise donation (referred to in this guidance as ‘parents’, but could include for example a legal guardian(s)) – they can do this wherever donation is an option, unless the Procurator Fiscal has refused to allow donation to proceed. It is up to the parents to make a decision based on what they feel their child would have wanted (where it is possible to know this). However, if the child is 12 or over and they are on the Organ Donor Register (ODR), that legally counts as them authorising their own donation. Children can also join the ‘opt out’ register if they do not wish to donate - if so, their decision should be respected – a parent should not authorise donation for their child if they know that the child did not want to be a donor.

Even where a child has authorised donation themselves, donation will be discussed fully with the child’s parents – while the conversation is approached somewhat differently where the potential donor is on the ODR, it is still important to involve the family and ensure they are comfortable with the process. The parents or other family members will need to provide information about their child’s medical and other history to help ensure that any organs or tissue are safe to transplant.

² See <https://www.rcpch.ac.uk/resources/diagnosis-death-neurological-criteria-dnc-infants-less-two-months-old-clinical-guideline>

Consideration of donation for unborn babies

Staff in neonatal units should also be aware that it is possible – although more challenging – for donation to be considered during pregnancy where the parents have been informed that their baby has a serious condition, such as anencephaly, and is not expected to survive. In such cases, preparations can be made in advance for donation to occur if the baby is born alive, but dies shortly after birth. Separate guidance on this is available for midwives, obstetricians and other health professionals caring for pregnant women³.

Guidance on key steps to progress donation

1) Exploring donation

The most important points for health professionals to remember are that donation should start to be considered at an early stage when you think a patient may die and that you should almost always check with a SNOD or TDC to see if donation may be possible, even if you think it's unlikely. They will be able to tell you quite quickly by phone if the child or baby could be a potential donor and this early screening call will help to ensure that no potential donor is missed.

It is usual practice in donation to have discussions with a SNOD or an initial discussion with a TDC before raising the prospect of donation with family members. This is important to make sure that donation is considered wherever possible, but isn't raised with families if it's definitely not going to be a viable option and also to ensure that it is not raised until the time is right and the family have accepted the inevitability of their child or baby's death. [NICE guidelines on organ donation](#) make clear that it is appropriate, and indeed important, to both carry out initial checks with a SNOD to consider whether donation may be in a patient's best interests and arrange for a SNOD to be involved in the initial discussion with family members about donation and plan to ensure it is approached in a way which is sensitive to the family's needs before having the a discussion with the family (while this guidance is written for England and Wales, it is very relevant for Scotland as well).

It is worth noting that the embedded SNOD who works in your hospital has an honorary contract with your NHS Board, which allows personal data to be shared with the SNOD, where appropriate, to enable donation to be considered and planned.

Below are the key steps in the initial process of exploring donation:

End of Life Care Planning - Unless the death is sudden, aim to **discuss donation with the child's parents as part of any end of life care plans** (their anticipatory

³ Available via <http://www.gov.scot/Topics/Health/Services/OrganDonation>

care plan or Children and Young Persons Acute Deterioration Management forms (CYPADMs)) so any wishes expressed by the child or their parents can be taken into account. This should be done in a general way to explore whether they would be willing to consider donation if their child dies, without placing pressure on the parents. While it is good to gather parents' initial views and start to introduce consideration of donation and how it could save others, it clearly needs to be approached sensitively. While in cases where the parents are firm that they do not want to be a donor their wishes should be respected, in some cases parents may feel unable to consider it at that time, particularly if they have not yet come to terms with the fact that their child is not going to survive. Therefore in cases where they don't respond positively, but don't rule out donation, this should be noted and you should do an initial screening check.

Initial screening check – in cases where the child or baby is not yet dead, but where you expect to either carry out brain stem death tests in the next 24 hours or where you expect to be recommending shortly to the family that life sustaining treatment should be withdrawn, you should contact the on call SNOD via the pager number **03000 20 30 40** at any time of day (or you can call the NHSBT office on **0300 123 9209** in office hours) to have an initial discussion about your patient and whether they may be a potential donor. If you have a local SNOD based in your hospital, you can contact them directly. This should happen **in all cases**, except where a baby is less than 36 weeks corrected gestational age. There is a list of some contra-indications to donation⁴, but this list changes periodically so please speak to a SNOD to check on the latest position.

The SNOD will ask you some questions about the patient's medical history to see if there are any reasons why a donation definitely could not proceed. In many cases for babies and children, the SNOD will often call transplant surgeons to see if the organs would be likely to be suitable for transplant based on the patient's medical condition(s) and the current patients on the transplant waiting list. The SNOD will also check if the patient is on the Organ Donor Register or if they have registered that they do not wish to donate (often known as 'opting out') – Scotland has the highest proportion in the UK of children who have registered their decision to donate on the ODR.

The SNOD will then call you back and let you know if the patient may be a potential donor. If they are, then they will arrange an appointment to come and visit the ward at an agreed time (see below) or agree to get in touch with you once further decisions have been made about the patient's treatment. Please note that this stage is just an initial and in confidence opportunity to explore the donation potential; it does not commit you to progressing a referral.

⁴ See http://odt.nhs.uk/pdf/contraindications_to_organ_donation.pdf for further information

NHSBT has developed a Scottish Integrated Care Plan for organ and tissue donation from neonatal or paediatric donors which aims to help critical care units to go through each step in the process with the SNOD and family members. If a patient is identified as a potential donor, you may wish to start using the Plan for the patient at this stage.

Checking with the Procurator Fiscal – where there is reason to believe that a death would need to be reported to the Procurator Fiscal ⁵, you should contact the Procurator Fiscal to discuss whether they agree that organ/tissue donation is permitted. In some cases the Procurator Fiscal may only permit a partial donation and may specify some conditions and in a few very serious cases they may refuse permission for the donation to proceed at all. The SNOD can help you if you have any problems or concerns about the response from the Procurator Fiscal – they may be able to help by providing reassurance to the Fiscal, for example, that the retrieval team of surgeons will examine and document findings in the patient during the operation.

Formal referral – if the SNOD has not already arranged to come to the unit as a result of the screening check above, the patient should be referred when the decision to withdraw treatment is documented or when brain-stem death testing is about to be carried out. You should call the on duty SNOD to do this – the on call pager number is **03000 20 30 40**. Even if the patient is not on the ODR, a referral should still be made as the patient may well not yet have been able to consider donation (clearly in the cases of babies and very young children, they will not have been able to understand the concept of donation, but their parents can still make a decision on their behalf). Even in cases where the patient had opted out of donation, a SNOD will still approach the family to double check that the patient had not changed their mind in order to ensure their most recent decision is taken into account – while this scenario is unlikely in the case of a child, it could happen.

A SNOD will then attend the unit. Apart from any general discussion as part of end of life care planning or cases where the parents themselves proactively ask about donation, donation should not be raised with a family until they have accepted that their child is going to die (in DCD cases) or have accepted the results of the brain-stem death tests (in DBD cases).

The SNOD should then be involved, alongside a clinician who has been involved in caring for the patient, in any discussion with the family about donation, as SNODs have a lot of expertise in discussing the subject with families. They will talk to you in advance to agree how best to approach the discussion and whether to involve anyone else. They will be able to guide you on how to introduce them to the family.

⁵ A complete guide for reporting deaths to the Procurator Fiscal is contained within: 'Reporting Deaths to the Procurator Fiscal - Information and Guidance for Medical Practitioners' available at: <http://www.crownoffice.gov.uk/publications/deaths> (see section 3 in particular)

This is important as the family is significantly more likely to be willing to allow donation to proceed in cases where a SNOD is involved. For example, in 2016-17, across all donors, almost 79.4% of families agreed to donation where a SNOD was able to explain it to them and discuss it with them in detail; only 10.9% of families agreed to donation in cases where no SNOD was involved in the approach to them.

If the family are willing to agree to donation, but are also keen that a hospital post-mortem should be undertaken, it should be possible to do both, depending on the likely cause of death, but the SNOD can explore with the pathologist to see if donation can occur in a way which will not impede a thorough subsequent investigation of the cause of death via the post-mortem.

Tissue Donation – if there is potential for the child or baby to donate tissue as well as organs, the SNOD will make the necessary arrangements with Tissue Donor Coordinator colleagues (the Scottish National Blood Transfusion Service (SNBTS) for the donation of heart valves as part of the organ donation process, or NHSBT colleagues for the donation of eyes).

However, if the patient is likely to be able to donate tissue only – for example if they have already died as a result of circulatory death - then you should normally contact SNBTS in the first instance. If you are not sure whether organs or tissue, or both, can be donated, then speak to a SNOD and they will refer you on to the relevant SNBTS Tissue Services or NHSBT eye donation colleagues if they think a tissue only donation could be possible.

The contact details are:

- SNBTS Tissue Services – **07623 513987** (24/7 on call radio page) – they can pass you on to the National Referral Centre for eye donation if they feel that only eye donation is possible.

The subject of tissue donation can be approached in the same manner as for organ donation. The TDC should be contacted prior to any conversation with the family. This ensures the appropriate information on any donation potential is given to the family. However, for tissue only donation, the TDC will usually speak to the family about donation by telephone, rather than face to face. If the family wish to speak face to face and there is a TDC available, they will do their best to attend. This is dependent on the location of the patient and of the TDC on call.

2) Progressing the donation – summary of key steps

In cases where the potential donor's parents are willing to authorise donation to proceed, these are the key steps in the process. The SNOD or TDC will let you know at the time anything that you need to do to help guide you through the process. As noted above, the Scottish Integrated Care Plan can help you through the process step by step – the Plan sets out the pathway for different types of donation (DBD –

donation after brain-stem death, DCD – donation after circulatory death or tissue only donation).

Donation normally takes some time to organise – in some cases, it can take more than 24 hours to allow for testing to take place, for the organs to be accepted by a Transplant Unit(s) and for the retrieval team to get to the hospital. This will be discussed with the family members, but you need to be aware that the patient will need to be kept stable in the unit until the donation is ready to proceed. Where there are no spare beds in a unit or the patient's bed is needed for a new patient, a child or baby with a prospect of survival takes precedence over a patient whose treatment is being sustained solely to prepare for donation. However, if this happens, clinicians and SNODs should explore whether there is a suitable bed available elsewhere for the potential donor, either in the same hospital or another hospital.

- The SNOD or TDC will go through a range of **questions with the child's parents** to try to identify any potential health conditions or other barriers to donation. They will also check the patient's medical records and try to speak to their GP (if they had one).
- The SNOD or TDC will guide unit staff on any **tests** that are needed (e.g. blood and urine tests and X-rays) and other preparations needed – these tests are necessary for tissue typing to find recipients who are a suitable match to receive the organs and also to check for any infections, such as HIV or hepatitis.
- All organs which could potentially be donated will be **offered to UK transplant units** (and occasionally to units in Europe if no UK unit can accept them) – only in cases where at least one organ has been accepted by a unit for transplantation will the donation proceed. In some cases though, other organs may be retrieved as well where the family have agreed that they can be donated for other purposes, such as research.
- A team(s) of **organ retrieval surgeons** will come to the hospital to retrieve the organs (occasionally there could be two teams – one retrieving abdominal organs, the other cardiothoracic organs, although often only the abdominal team will attend). The teams treat all donors with great care and dignity. Afterwards, the surgical incision is carefully closed and covered, and arrangements for viewing the body after donation are the same as after any death.
- If the patient is going to donate their **heart valves** as well as some organs, the heart will be retrieved by the retrieval surgeons when the other organs are being retrieved. However, if the patient will be a tissue only donor, they will generally require to be moved to the paediatric mortuary at the Queen Elizabeth University Hospital site in Glasgow for tissue retrieval to be undertaken - Paediatric Pathologists will retrieve the heart, working with Tissues Specialist Retrieval Staff. The donation of heart valves must be undertaken within 48 hours of the child's death. SNBTS will arrange this with the permission of the child's parents. The child's body will be returned as soon as possible afterwards so that there will be no delay to the burial process.

- **Eye donation** will only take place after it is ascertained that there is a requirement for donation from such a young donor (children aged three years old or over can potentially become eye donors) – if eye donation is appropriate and has been authorised by the child’s parents, then a specialist in eye retrieval will come to the hospital to carry out the retrieval soon after death (this has to happen within 24 hours of the child’s death). This is done sensitively and the eyes are filled in afterwards so that it just appears that the child’s eyes are closed.
- Where the donor is going to have a **post-mortem** (either a hospital post-mortem or one ordered by the Procurator Fiscal), this will be carried out after the organs have been donated. In the case of heart valve donation, the process of heart valve donation will be undertaken before the post mortem begins. The post mortem should (in normal circumstances) be carried out as soon as possible afterwards. This is so that the child can be returned to their family as soon as possible for their funeral to take place.

Conclusions

This guidance aims to provide an overview of the potential for donation and key steps in the process. A SNOD or TDC can provide you with advice if you have any queries at all about the process generally or any specific patients. They are there to help you and the donor families through the process.

Your support in ensuring that donation is routinely offered to families as an option as part of neonatal and paediatric patients’ end of life care will not only help save lives, but can also bring great comfort to donors’ families over time.

Appendix

Key contacts

NHSBT organ donation pager (can be used 24 hours a day, 7 days per week) -

03000 20 30 40

NHSBT Falkirk office – 0300 123 9209

SNBTS Tissue services pager (24 hours a day, 7 days per week) - **07623 513987**