



**Blood and Transplant**

# **The Journey Through Intensive Care and the Gift of Organ Donation**





# The Journey Through Intensive Care and the Gift of Organ Donation

The aim of this document is to summarise the possible journey of a person suffering a life-threatening injury through to intensive care, which sometimes may lead to the potential for deceased organ donation. It brings together the key points from a wide range of NHS policies, protocols and legislation relating to intensive care and organ donation.

The target audiences for this document are:

- members of the public who wish to know more about intensive care processes and organ donation;
- stakeholders such as patient representative groups and donor families;
- faith groups;
- hospitals;
- donation advocates.

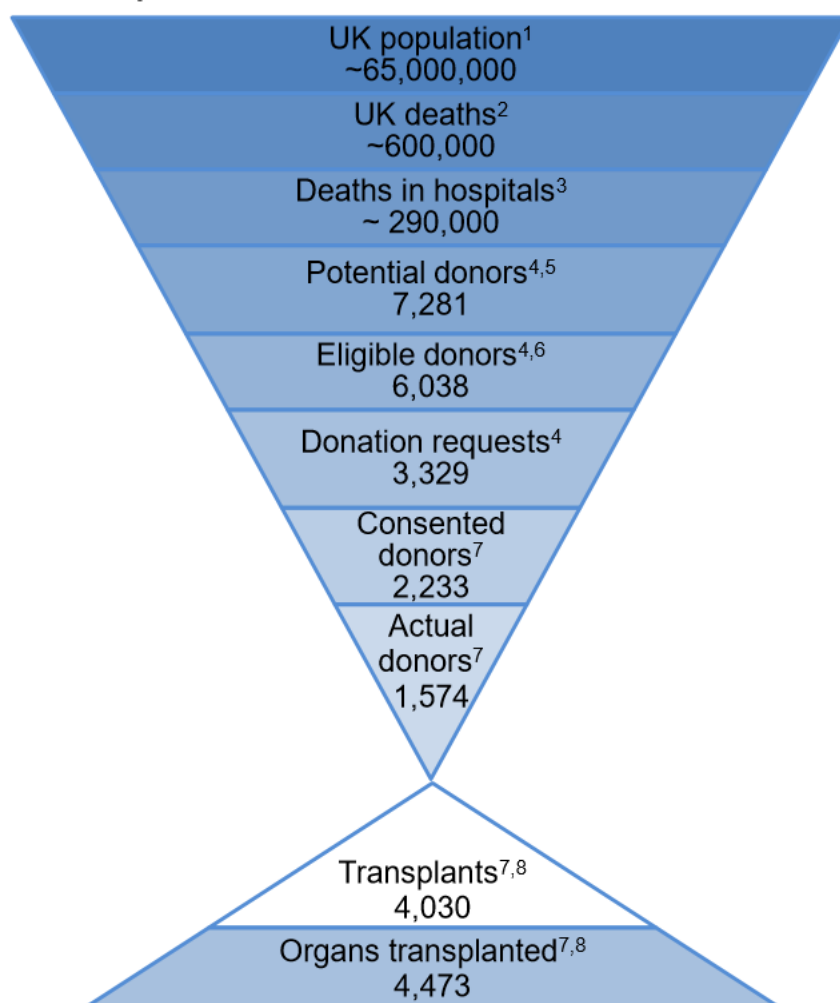
This document will outline some common journeys through intensive care and where it may be appropriate to discuss organ donation.

## Introduction to organ donation

Every year, thousands of people have their lives saved or dramatically improved through the gift of organ donation and the incredible generosity and altruism of donors and their families, who think of others at a time of tragic loss.

Around 600,000 people die every year in the UK, but only around 1 in 100 of them die in circumstances where they can donate their organs. Organs can only be transplanted very soon after someone has died and the donated organs need to be in a suitable condition to be safely transplanted. Donors can usually only be people who have died in a hospital intensive care unit or accident and emergency department.

## UK potential deceased organ donor population, 1 April 2017 – 31 March 2018



1 Mid 2016 estimates: [www.ons.gov.uk](http://www.ons.gov.uk)

2 2016 data: England & Wales [www.ons.gov.uk](http://www.ons.gov.uk); Scotland [www.gro-scotland.gov.uk](http://www.gro-scotland.gov.uk); Northern Ireland [www.nisra.gov.uk](http://www.nisra.gov.uk)

3 2016 data: England & Wales [www.ons.gov.uk](http://www.ons.gov.uk); Scotland [www.isdscotland.org](http://www.isdscotland.org); Northern Ireland [www.nisra.gov.uk](http://www.nisra.gov.uk)

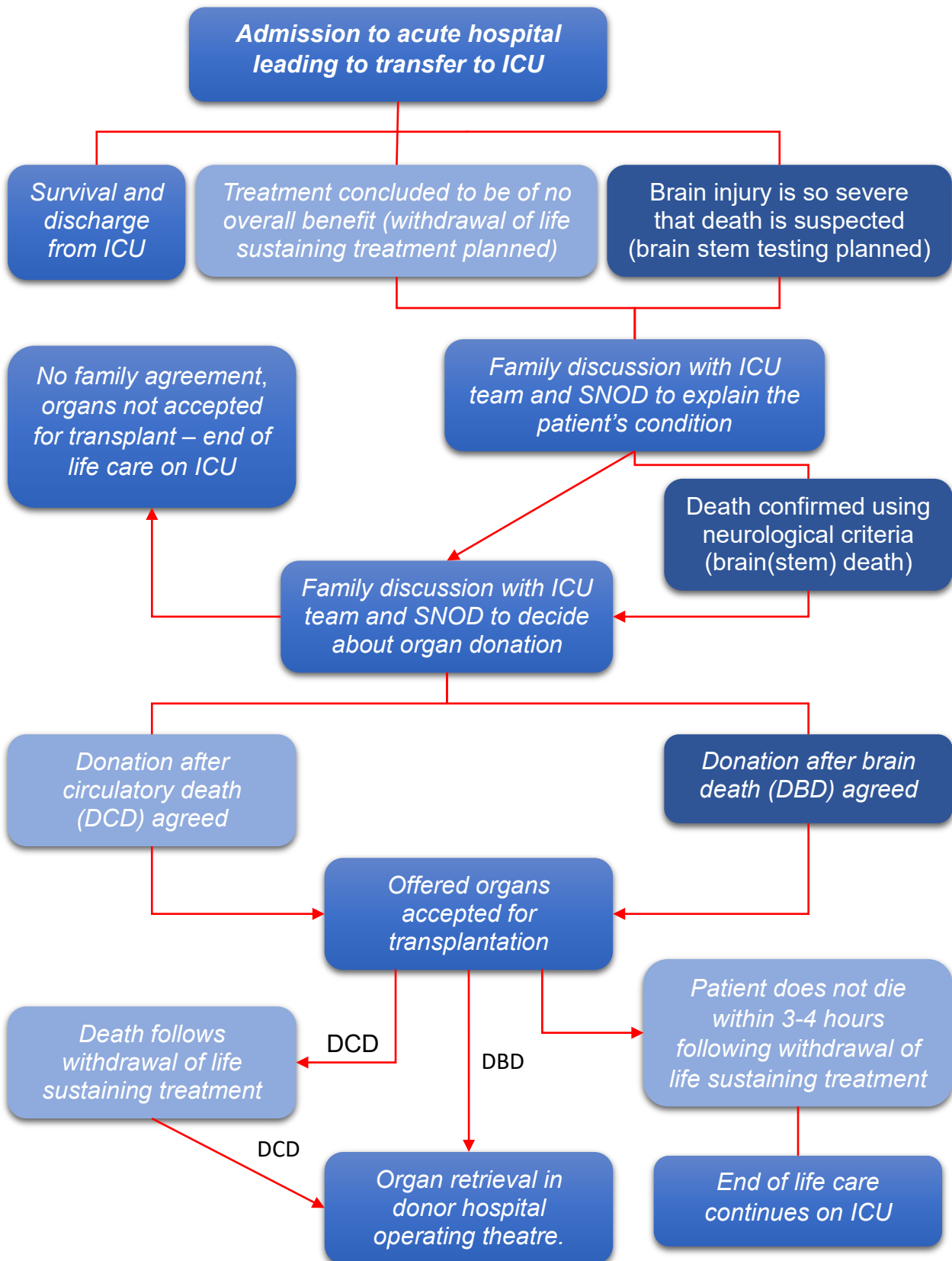
4 2017/2018 data: NHSBT, Potential Donor Audit

5 Potential donor - patients for whom death was confirmed following neurological tests or patients who had treatment withdrawn and death was anticipated within four hours

6 Eligible donor - Potential donor with no absolute medical contraindications to solid organ donation

7 2017/2018 deceased donor data: NHSBT, UK Transplant Registry 8 Using organs from actual donors in the UK

# Overview of the intensive care journey and deceased organ donation



## 1. Emergency hospital admission

Most patients that become organ donors have suffered from an unexpected brain injury, either as a result of trauma, bleed within the brain, stroke, or due to a lack of oxygen from a cardiac arrest. At the point where this injury occurs and because the patient is usually unconscious, they will be connected to a ventilator which will take over their breathing. They may also be given drugs which will keep them asleep, before being taken to an intensive care unit.

Steps are taken as soon as the NHS becomes involved in the care of a patient to access information regarding medical history, General Practitioner (GP), place of residence and next of kin. Should the patient have been brought in by ambulance, the ambulance staff will in addition have asked relatives or friends or those with the patient at the time of their emergency for any further information that they may have. These details are then merged with any information that the hospital may already have on the patient.

## 2. Intensive Care admission

Following admission to the intensive care unit, the focus for the doctors and nurses is to try and save the life of the patient, and to assess the degree of injury that the brain has suffered. During this period, which may last for many days, the intensive care staff will make further efforts to find out more about the patient. These will include regular meetings with relatives, calling their GP to gain access to the 'Summary Care Record', and contacting other hospitals should they previously have been cared for elsewhere.

A part of the assessment also relates to wider issues that may be of importance to the patient and their family. These would include religious, faith & cultural beliefs, identifying those who are close to the patient (if not already known), such as family and friends, so to build a more detailed picture of the person that is being cared for. This is sometimes referred to as 'Getting to know you' and is an essential part of the intensive care process and documentation. Should it prove difficult to contact relatives, hospital staff would contact the police, embassies and any other relevant resources to trace the family to gain the information essential to their care. Pastoral support is offered at this difficult time for families.

## 3. Intensive Care treatment

All clinicians would hope that the treatment that they provide allows the patient to achieve a full recovery and return home. However, there are unfortunately times when, despite the best efforts of the intensive care staff, the injury is too severe for the patient to survive. Intensive care mortality in the UK is around 15% (15 in every 100 admissions) and for those admitted as an emergency, this figure is much higher.

The doctors and nurses will regularly meet with the families of their patients and will keep them informed at all times about the treatment and expected outcome. There are usually several meetings, some in a sit-down room close to the intensive care, over the course of

the intensive care admission, so family and friends are fully aware what steps are being taken to try and save the life of their loved one. The results of various blood tests, scans and other investigations may be discussed during these meetings. The family will always have opportunities to ask questions and would receive truthful, albeit sometimes difficult to hear, answers. They may also be asked questions relating to what their loved one regarded as important, what sort of life they would want to live, and if they had ever had any conversations regarding what they would have wanted should they find themselves in this situation. While decisions regarding medical care are the remit of the doctors, they will endeavour to work with families, and have a legal responsibility to work with families and those close to the patient, at what is an incredibly difficult and distressing time.

## **4. Confirmation of death using neurological criteria or determination of a ‘best interests’ decision to withdraw life sustaining treatment**

There are two intensive care journeys which may result in a patient becoming an organ donor after their death, following confirmation of death using neurological criteria or following a ‘best interests’ decision to withdraw life sustaining treatment.

### *Confirmation of death using neurological criteria*

It sometimes becomes clear to the medical team during the period of treatment & assessment that the patient’s brain injuries are so severe that the patient may have already died; even though the patient’s heart continues to beat owing to intensive care providing ventilation to the lungs. To make this diagnosis, two senior doctors carry out bedside tests of the patient’s brain function to see if death has occurred and can be confirmed using neurological criteria (also known as testing for ‘brainstem death’).

Before undertaking the tests, the doctors must be certain about the cause of the brain injury and that no other conditions could influence the assessment. In the majority of cases where death is suspected, the tests to determine death using neurological criteria would not be undertaken until at least 24 hours of assessment. There will usually have been several family meetings where the increasingly bad news has been explained. Should the medical team believe that it is possible to make this diagnosis, the benefits of testing are:

- establishes if the patient is alive or dead (and this is accepted in UK law),
- eradicates doubt, which can be of benefit to the family and the hospital staff, and
- allows futile and/or inappropriate treatment to cease.

This testing is undertaken by two senior doctors, one of whom must be a consultant. Both doctors need to have been qualified for more than five years, and competent in undertaking the tests for diagnosing death using neurological criteria.

The conduct of the testing is underpinned in the UK by a Code of Practice issued by the Academy of Medical Royal Colleges (available at: [http://aomrc.org.uk/wp-content/uploads/2016/04/Code\\_Practice\\_Confirmation\\_Diagnosis\\_Death\\_1008-4.pdf](http://aomrc.org.uk/wp-content/uploads/2016/04/Code_Practice_Confirmation_Diagnosis_Death_1008-4.pdf)).

A series of education videos have been created by NHS Blood and Transplant, and though the intended audience are healthcare staff, it is available to the public, and can be watched at: <https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/donation-after-brainstem-death/diagnosing-death-using-neurological-criteria/>

When doctors carry out this diagnosis they use forms endorsed by the Faculty of Intensive Care Medicine (FICM) Abbreviated version of the form is available at: [https://www.ficm.ac.uk/sites/default/files/Form%20for%20the%20Diagnosis%20of%20Death%20using%20Neurological%20Criteria%20-%20Abbreviated%20Version%20\(2015\)\\_0.pdf](https://www.ficm.ac.uk/sites/default/files/Form%20for%20the%20Diagnosis%20of%20Death%20using%20Neurological%20Criteria%20-%20Abbreviated%20Version%20(2015)_0.pdf)

Full guidance and copies of the form are available at: <https://www.ficm.ac.uk/sites/default/files/Form%20for%20the%20Diagnosis%20of%20Death%20using%20Neurological%20Criteria%20-%20Full%20Version%20%282014%29.pdf>

Before undertaking the tests, the two senior doctors must agree on the existence of the following:

1. Evidence of irreversible brain damage of known cause.
2. The exclusion of reversible causes of coma and apnoea (the inability to breathe).
3. The results of tests which demonstrate the absence of brain-stem function.

Should any of these criteria not be met, the doctors would be unable to diagnose death using neurological criteria and the implications and plans for ongoing treatment will be discussed with the family.

In some of these cases, doctors agree that the tests do not demonstrate that the patient has died. The patient's clinical condition may remain static, and in a very small proportion there may be improvement, in which case active treatment will be continued and the patient may recover some or all of their neurological function and be discharged from intensive care. Sadly, even if death is not confirmed, it does not mean the patient will recover as the patient still has a severe brain injury.

### *A 'best interests' decision to withdraw life sustaining treatment*

In some cases, the medical team may conclude that, despite what they are doing to try to save the patient's life, the treatment is not working, and that death is inevitable.

Alternatively, it may become apparent to the medical team that the patient has permanent and severe brain injury and will not make a good recovery. Through conversations with family and friends it may be clear that the patient would not wish to survive with this degree of brain damage and disability. These are intensely personal decisions, and the medical team will sensitively help the family to understand what truly are the patients 'best interests', as defined legislation (including the Mental Capacity Act of 2005 in England and the Adults with Incapacity (Scotland) Act 2000). These are wider than just their medical best interests, and includes values, wishes and beliefs, and the team always set great store by what families tell them.

The result of these possibilities is that in consultation with the family, a decision is made to change the focus of care and accept that death is inevitable. Palliative care is then put



in place, if appropriate, and treatments that may prolong the dying process are stopped. This usually includes disconnecting the patient from the ventilator and removing the breathing tube and providing comfort measures to ensure a dignified and comfortable death. These decisions would all be discussed with the family, as would their timing. Pastoral support for the family is also an important factor at this time.

It is important to note that decisions regarding: the confirmation of death using neurological criteria; the 'best interests' of the patient; or the discontinuation of futile treatments, are entirely separate from considerations regarding organ donation, and will be made whether or not there is any possibility of donation.

There are rare occasions when 'best interests' decisions are made and life-sustaining therapy is stopped, that the patient does not die. The doctors and nurses looking after the patient will then discuss with the family whether end of life care is appropriate, or whether further efforts should be made to save the life of the patient, depending on the degree of recovery.

## **5. Referral to the Specialist Nurse for Organ Donation**

Following a decision to diagnose death using neurological criteria or to consider withdrawal of life sustaining treatment (and before undertaking the tests/ withdrawal of life sustaining treatment), the intensive care team caring for the patient will make a referral to the Organ Donation service. An initial assessment will be made on the information given by the medical team. If the patient appears to be a potential organ donor, a Specialist Nurse for Organ Donation (SNOD) will attend the hospital to carry out a more in-depth assessment. The SNOD will access the Organ Donor Register (ODR) at this point, to establish if the patient had made a decision in advance about organ donation.

Donation can only take place after a diagnosis of death has been made. Depending on the circumstances, this will be made as either:

- i. neurological criteria (referred to as Donation after Brainstem Death, DBD),
- ii. circulatory criteria (referred to as Donation after Circulatory Death - DCD, where following discussion with the family, life-sustaining treatment has been withdrawn. In line with guidance issued by the Academy of Medical Royal Colleges in 2008, donation occurs only after the heart has stopped beating for five minutes and death has been confirmed.

## **6. Donation Conversation**

There are occasions when the option of organ donation is not possible, for example, despite maximum therapy the patient's heart stops beating unexpectedly or the patient's medical history means the organs could not be safely transplanted (e.g. if the patient has a diagnosis of cancer). In such circumstances, donation would not be appropriate.

If the patient appears to be a suitable organ donor following further assessment, then the SNOD will work closely with the doctors and nurses to support the family, through the confirmation of death using neurological criteria (if occurring) and through the breaking bad news conversations. The SNOD will try and ensure that the option of donation is only raised when the grieving family are ready and able to consider it... The family will be given opportunity to consider any other family members that may want to be present for the breaking bad news conversation. This includes friends or relatives that may live further away, religious/ faith/ belief representatives etc. Wherever possible, the discussion will be delayed until everyone the family has requested can participate.

During the discussion, the SNOD will provide information about any decision their family member may have made on the Organ Donor Register (ODR), whether it was to donate some/all organs, or not to donate any organs. The SNOD will tell the family the date and route for recording their ODR decision (e.g. through the ODR website, as part of a driving licence application). If the family are aware of a more recent donation decision than that recorded on the ODR, they will be invited to share that with the SNOD. Should the patient not have recorded a donation decision, the family will be approached to seek their views on whether their family member would have wanted to donate.

When the Organ Donation (Deemed Consent) Act 2019 – more commonly referred to as “Max and Keira’s Law” or ‘opt out’ – legislation is implemented in Spring 2020, this process will still apply and the family of a potential donor will always be approached for their views and advice about whether donation should proceed. Under the new law, a donation decision can be recorded on the ODR or expressed as part of a discussion with the people close to the deceased. Each method carries equal weight and is the reason why the family will always be included in the discussions about donation. Where an individual has not recorded any donation decision and had never discussed donation with the family their consent can be ‘deemed’, but again, the SNOD will seek to gain the family’s support for donation to proceed and explore what their loved one would have wanted.

The SNODs will work sensitively with family members who disagree about whether donation should proceed, with the aim of reaching an agreement that takes into account the most recently expressed decision of the patient. In cases where the family are unable to reach an agreement, the Human Tissue Authority Codes of Practice set out a hierarchy for consent.

Where no individual in a qualifying relationship can be traced and there is no record on the Organ Donor Register that they wanted to donate, organ donation is not possible. If there is a decision to donate recorded on the Organ Donor Register but it is not possible to trace any family or friends, consent would be in place. However, it is still unlikely that donation would proceed. This is for the protection both of the patient and any recipients of organs, as the family play a key part in providing the team with medical information.

## 7. Consent & Authorisation

If the family supports an existing organ donation decision or gives consent for donation to proceed, the SNOD will provide them with information regarding what happens next and the process. They will be supported throughout and will be given the opportunity to discuss any concerns and ask questions. Any specific needs, such as religious or cultural practices, will be discussed and the SNODs will endeavour to fulfil any requests. This would include, for example, washing of the body, any specific funeral requirements, the operating table facing Mecca. Formal/ legal paperwork needs to be completed with the family and the consent/authorisation form will be signed at this point. A full medical and social history questionnaire will be completed with the family to ensure the SNOD has the necessary information about the patient's medical, social and travel history. A copy of the consent form can be given to the family if they wish.

## 8. Collecting information & matching organs to recipients

The SNOD will attempt to gain as much information about the patients' medical history as possible. Following on from the family discussions, the SNOD will contact the patient GP to gain any further information. They will also read all the hospital notes from the current stay to any previous admissions. The patient's height and weight will be recorded, and a full body examination will be carried out to check for anything that has not been identified which may be of concern, for example operation scars or discoloured moles. All the information obtained about the patients' medical history will be placed onto a secure database which can be accessed by the transplant centres. Blood samples will be sent for testing for any infections and typing laboratory, to ensure we find the best possible match for the organs. Once all this information has been inputted onto the secure database and the blood results are complete then the transplant surgeons will access this information and make decisions as to whether they have suitable transplant patients on the transplant waiting list. The organs will be offered to the transplant centres dependant on the tissue typing and the patients' blood group. The transplant centres will then make a decision taking into account all the information about the donor and the patients they have waiting for transplants. The family are able to spend extra time with the patient up until they go to the theatre for the operation.

## 9. The Organ Donation Operation

Once an organ has been accepted for a transplant patient, a specialised national organ retrieval team will be asked to attend the hospital where the donor patient is being cared for to carry out the operation. The retrieval teams are independent of the hospitals and are made up of highly skilled transplant surgeons and nurses. On arrival the retrieval team will go straight to the theatre and will have no contact with the family or the patient until the patient is moved to theatre for the operation. The SNOD will ensure that the

team have been given a full handover regarding the patient's admission and medical history as well as which organs or tissues have consent for retrieval.

If death has already been confirmed on the intensive care unit using neurological criteria, the patient will be moved to the operating theatre for the retrieval operation. In Donation after Circulatory Death, a decision may be made for the withdrawal of life sustaining treatment to take place on either the Intensive Care Unit or near the operating theatre. This decision is based on routine practice in that hospital to make sure that the organs donated are in the best possible condition to ensure a successful transplant, and that good end of life care can be delivered. In DCD, time is of the essence and the Organ Donation Operation must start as soon as possible after the 5 mins of heart inactivity (known as asystole).

There are occasions in DCD where following the withdrawal of life-sustaining treatment the patient does not die within the first three hours. In those cases, organ donation can no longer occur (though tissue donation could still occur after death) and the patient would be returned to the intensive care unit where sensitive end of life care would be continued.

Once the patient is moved into the operating theatre the team will carry out the operation in a dignified and respectful way just as they would for any other operation. This is an amazing gift that the donor is giving and the surgeons recognise this. After the organs have been retrieved, the organ retrieval surgeons will ensure that the wound is carefully closed and dressing is placed over the wound. The retrieval team then leaves the hospital. The SNOD will ensure that the organs are safely transported to the allocated hospitals as soon as possible, so that they can be transplanted into the waiting recipient.

## **10. After the donation is complete**

After the operation the patient will continue to be cared for by the SNOD. If the family wish to see the patient following theatre, this will be arranged. The SNOD will telephone the family if they have left the hospital and inform them of the outcome. If there are any specific requests from the family, such as washing of their loved one or quick release of the body for funeral arrangements, then this will be organised. If the family wishes, the SNOD will send them a letter a few weeks later giving information regarding their family members donation.

All deceased organ donors are eligible to receive The Order of St John Award for Organ Donation, and tissue donors, The Order of St John Award for Tissue Donation, which families can accept on their loved one's behalf.

# Consent/Authorisation

## *Donation for transplantation purposes*

Donated organs will only be used for transplant with consent/authorisation in place. This consent/authorisation can be through one or more of several routes:

- The individual registering a decision on the Organ Donor Register about which organs and/ or tissues they would like to donate after their death
- The individual telling their family/ friends about wanting to donate some or all of their organs and tissues after their death
- The individual appointing someone to make the decision about organ donation on their behalf

Where there is no known decision about organ or tissue donation, under the Human Tissue Act, the family member(s) are asked for consent for donation. In Spring 2020, the Organ Donation (Deemed Consent) Act 2019 – commonly referred to as ‘opt out’ or ‘deemed consent’ – will be applied. Under this new law, if there is no known decision (either on the Organ Donor Register or through previous conversations with family and friends), the family members will be consulted about whether the patient would have wanted to donate.

The Human Tissue Authority provides guidance on what constitutes lawful consent to organ and tissue donation, after death has been diagnosed. Their guidance is available at: <https://www.hta.gov.uk/hta-codes-practice-and-standards-0>

## *Donation for novel or rare types of transplantation*

When consenting to organ donation the family will be consulted about the potential for donating for new/ novel forms of transplant. These are split in to two main categories:

- i. Rare donation – this is the donation of organs or tissues for transplants that are already offered within the NHS, but are very rare, such as arm or hand transplants.
- ii. Novel donation – this is donation of organs or tissues where a new type of transplantation is being evaluated to see whether it would be safe and effective to provide to NHS patients. Some of these types of transplant have successfully taken place elsewhere in the world. For example, face and uterus transplantation.

These types of donation are normally limited to a small number of hospitals, where the staff fully understand the process. For both these types of donation, the family would be approached and the SNOD would explain what could be donated and respond to any queries. Donation would only proceed if the family had given their express consent.

## *Donation for research and development purposes*

Research and innovation drives improvements in patient care and treatments and NHS Blood and Transplant works in partnership with leading universities and research

institutes. Organs and tissues will only be used for research purposes if the family gives their express consent.

During the consent conversation the SNOD will discuss what would happen if the organ could not be transplanted for any reason - for example, the retrieving organs determines that one or more organs would not be suitable for transplant. Alternatively, on some occasions the surgeon undertaking the transplant operation examines the organ and decides that it cannot be safely transplanted in to their recipient. If the organ had already been retrieved for transplant purposes but the surgeon decides it is not safe to transplant, then it could not be returned to the body and would be appropriately disposed of.

If the family consent to research, then the organ would go on to a research project. The family are given information by the SNOD about the types of research in which the organs might be used. This would include information about whether the research may include genetics, commercial interests or animals. These options will all be discussed in depth by the SNOD and the family.

If the family consent this will be documented on the consent form which is signed by the SNOD and the family. The family may have a copy of this form if they wish.



## **NHS Blood and Transplant**

NHS Blood and Transplant (NHSBT) saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England. We are the organ donor organisation for the UK and are responsible for matching and allocating donated organs. We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells.

### **For more information**

Visit [nhsbt.nhs.uk](https://nhsbt.nhs.uk)

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