

**Brighton & Sussex University Hospitals
NHS Trust Hospital Policy on Organ
and Tissue Donation**

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1. POLICY STATEMENT

- 1.1 When patients die in hospital currently the option of donation is not considered in **all** cases where donation is a possibility. This can result in individuals' wishes not being identified and respected. It can potentially add to the distress of bereaved families who are denied the option of donation and ultimately affecting the positive benefit in lives saved or lives enhanced through transplantation.
- 1.2 The BSUH NHS Trust recognises the need to maximise the opportunities for donation in support of individuals wishes and embraces the acceptance of donation as an integral part of all end of life care in areas across the Trust.
- 1.3 In acknowledging the sensitivities surrounding donation practice, this policy provides clear guidance and procedures for organ and tissue donation and has been written to reflect public opinion, current legislation, existing codes of practice and recent Department of Health directives.

2. KEY PRINCIPLES

- 2.1 To ensure that explicit wishes of an individual in relation to organ and/or tissue donation after their death are identified, acknowledged and respected and where appropriate referred to external specialist teams to be carried out in a respectful, sensitive and dignified manner.
- 2.2 To ensure that donation discussions are an integral component of all end of life care pathways and to ensure that all bereaved families are offered the opportunity to consider organ/tissue donation in a timely and sensitive manner by trained staff who have access to specialist advice
- 2.3 To ensure staff who are directly involved in the identification and care of potential organ/tissue donors have the appropriate knowledge and skills and have undergone training to meet their level of need.

3. SCOPE

- 3.1 This policy applies to all staff working in all clinical areas who have direct contact with dying patients who are still being cared for within the Trust and/or their relatives or those who have recently died. It applies to adults, children and newborn.

4. CLASSIFICATION OF ORGAN AND TISSUE DONORS

Organ donors

- 4.1 Patients for whom the option of organ donation can be considered are primarily those who have suffered a catastrophic neurological injury which has resulted in the patient being declared Brain Stem Dead. These patients require ventilatory support and are therefore cared for in the Intensive Care Unit (ICU). A referral for neurosurgical opinion and subsequent transfer may be indicated, however where surgical intervention is not indicated and transfer to neurosurgical ICU is not appropriate, patients may remain on the general ICU.
- 4.2 Very occasionally a patient may present with a catastrophic neurological injury in the Accident and Emergency department (A&E). If transfer to ICU is not considered appropriate or not possible and the prognosis is regarded as very poor, donation can still be considered. Advice should be sought from the Donation Nurse Specialist or the Regional on call Donor Transplant Coordinator prior to any discussion with the patient's family/next of Kin. The Donor Transplant Coordinator, in conjunction with medical staff in Accident & Emergency, ICU and anaesthetic departments, will make necessary plans regarding raising donation prior to any donation discussion with the family.
- 4.3 Organ donation is also possible in some patients who have suffered a severe neurological injury but are not brain stem dead and where it is considered in the patient's best interest to discontinue active treatment. This option is referred to as donation after cardiac death. Those patients suitable for consideration of donation after cardiac death are those where there is a primary neurological injury and limited systemic disease. For this reason donation after cardiac death is only considered in ICU at Hurstwood Park and Princess Royal ICU.

Tissue donors

- 4.4 It is possible to donate tissues in patients for whom brain stem death is not a likely diagnosis but who die on ICU or A&E or in medical & surgical wards, palliative care wards or hospices. Unlike solid organs, body tissues do not deteriorate immediately after death due to their low metabolic needs.
- 4.5 In adults, eye tissue, heart valves, skin and bone can be retrieved up to 24 hours after death. In many cases there are no age restrictions and patients in their 80's and 90's can be considered suitable.
- 4.6 Eye donation is possible in children over 2 years of age as is heart valve donation in children from 6 months of age.

- 4.7 It may be possible to retrieve suitable heart valves from newborn babies if born at full term. Advice should be sought from the Donor Transplant Coordinator

Organ Donation

5. Notification to the Donor Transplant Coordinator

- 5.1 It is the responsibility of the ICU Consultant to notify the Donor Transplant Coordinator in all cases where the following criteria has been met¹

Donation following Brain Stem Death

When no further treatment options are available or appropriate, and there is a plan to confirm death by brain stem death testing, the ICU consultant or their designate should notify the Donor Transplant Coordinator either as soon as sedation/analgesia is discontinued or immediately if the patient has never received sedation/analgesia. This notification should take place even if the ICU Consultant believes that donation might be contra-indicated or inappropriate.

Donation after cardiac death

In the context of a catastrophic neurological injury, when no further treatment options are available or appropriate and there is no intention to confirm death by brain stem death testing, the Donor Transplant Coordinator should be notified when a decision has been made by the ICU and neurosurgical consultant to withdraw active treatment. This notification should take place where there is evidence of the individual's wish and/or a spontaneous request from the family/next of kin even where the ICU Consultant believes that donation after cardiac death might be contra-indicated or inappropriate

- 5.2 **The Donation Nurse Specialist works within the Trust and is available weekdays 08.00 hours to 18.00 hours and can be contacted on 0778 7530926. Out of hours the regional on call Donor Transplant Coordinator provides the same service and can be paged on 08700 555500 quoting code TC 20.** Since both roles provide the same service and the service is available 24 hours a day this policy from here on uses the term Donor Transplant Coordinator to cover both roles.

6. Assessing the option of organ donation after Brain Stem Death

- 6.1 On notification, the Donor Transplant Coordinator will determine whether the deceased had registered on the NHS Organ Donor

¹ DH Jan 2008 Organs for Transplant: A report from the Organ Donation Task Force. . www.dh.gov.uk

Register and thus consented to consideration for donation^{2 3}. The only absolute contraindication to donation being HIV and suspected CJD.

- 6.2 Unless spontaneously requested by the patient's family/next of kin, **donation should not be discussed at this stage**. Identification of the individual's wishes, an assessment of donation suitability and families/next of kin's understanding of the diagnosis is paramount before donation is raised.
- 6.3 It is the responsibility of the ICU Consultant to carry out brain stem death testing in accordance with the code of practice⁴ in all patients where brain stem death is a likely diagnosis **even if organ donation is an unlikely outcome**.¹
- 6.4 The exception is in children under 2 months of age where brain stem death can not be clearly diagnosed⁵. In these cases advice should be sought as to donation options after cardiac death.
- 6.5 The diagnosis of brain stem death is carried out by at least 2 medical practitioners who have been registered for more than 5 years, are competent in this field and are not members of the transplant team. At least one of the doctors should be a consultant.
- 6.6 Two sets of tests should always be performed; these may be carried out by the two practitioners separately or together. The timing of the interval between the tests is a matter of clinical judgement but the time should be adequate for the reassurance of all those directly concerned.
- 6.7 The time of death is recorded as the time when the first set of tests were performed. This must be documented clearly in the patient's medical notes and signed by both medical doctors. The relatives should be fully informed throughout the process and must be given time to understand this information **before being approached about organ donation**. Brain stem death testing forms and the code of practice for brain stem death testing can be found on the BSUH intranet (supporting patient care/ICU/organ donation)
- 6.8 In cases where brain stem death is not confirmed the decision will be the responsibility of the ICU Consultant as to whether treatment will continue or treatment will be withdrawn. In cases where the decision has been made to withdraw treatment, advice should be sought from

² **Human Tissue Act 2004** Code of practice 2: Donation organs, tissues and cells for transplantation. Human Tissue Authority. www.hta.gov.uk

³ **Intensive Care Society 2005** guidelines on the management of organ donors www.uktransplant.org.uk

⁴ **The Department of Health, 1998** The Working Party of the Royal College of Physicians on behalf of the Academy of the Medical Royal Colleges '**A Code of Practice for the Diagnosis of Brain Stem Death**'.

⁵ **British Association of paediatricians 1991** Paediatric guidelines for BSD testing.

the Donor Transplant Coordinator on the option of donation after cardiac death and tissue donation should be explored. Since death has not been confirmed, the patient should be placed on the Liverpool Care pathway for Critical Care which can be found on the BSUH intranet (Supporting Patient Care/ liverpool care pathway)

7. Offering the option of organ donation

- 7.1 In collaboration with the ICU consultant, it is the responsibility of the Donor Transplant Coordinator to assess the appropriateness and timing of raising donation as determined by the patient's medical history and the family's ability to accept the diagnosis. It may be appropriate to delay discussing donation until the family have had time to accept that death has occurred. **It must be noted that a premature approach to the family almost always results in them declining the option of donation. This potentially can lead to regrets later regarding their decision not to donate.**
- 7.2 After the first set of tests the Donor Transplant Coordinator will accompany the ICU Consultant in explaining brain stem death to the family/next of kin. This is to ensure that a consistent message regarding the death is reinforced in all further discussions. If felt appropriate, and only once the family have demonstrated an understanding that death has occurred, will donation be raised
- 7.3 The ICU Consultant and the Donor Transplant Coordinator will determine the appropriate person to make the approach. The person that makes the approach must feel confident and have an understanding of organ and tissue donation. It is important that this person can devote time to supporting the decision making process
6 7 8 9
, , ,
- 7.4 The families of all potential donors should have access to the specialist knowledge provided by the Donor Transplant Coordinator during the decision making process. This requires face to face discussions.
- 7.5 The use of a **collaborative approach** i.e. joint approach between the ICU Consultant and the Donor Transplant Coordinator can provide the best situation for families to make an informed decision¹⁰. The Donor Transplant Coordinator is able to devote unlimited time to support the family and can provide appropriate information to answer immediate

⁶ DeJong et al 1998. Requesting Organ donation: An interview study of donor and non donor families. American Journal of critical care. Jan 1998

⁷ Burroughs et al 1998. The stability of family decisions to donate or refuse organ donation. Would you do it again? Psychsomatic medicine.

⁸ Verble & Worth 2000. Fears and concerns expressed by families in the donation discussion. Progress in Transplantation. March 2000

⁹ Squa et al 2003 Organ and tissue donation: Exploring the needs of families. Executive summary

¹⁰ UK Transplant 2003 Hospital Policy for organ and tissue donation.

questions. It is recognised that any delay can have a detrimental effect on their experience⁹.

- 7.6 All major religions support the right of the individual to consider donation. Information leaflets are available from the chaplaincy on individual religious. See Religions and cultures booklet available on the BSUH intranet (Supporting Patient Care/spiritual and Religious Care Website. An A-Z of religious Beliefs and practices)
- 7.7 It is the responsibility of the Donor Transplant Coordinator and the ICU Consultant to document all discussions and their outcomes with family/next of kin in the patient's medical and nursing notes.

8. Obtaining consent

Where the patient is registered on the NHS ODR

- 8.1 Where there is a signed donor card or registration on the NHS Organ Donor Register this represents consent of the individual for donation and as such is sufficient consent for donation to be lawful²
- 8.2 In such cases it is the responsibility of the Donor Transplant Coordinator to inform the deceased person's relative or those close to them and encouraged them to respect their wishes.
- 8.3 In cases where there are no relatives or friends it is lawful to proceed. However the Donor Transplant Coordinator must discuss with the Transplant surgeons who will take responsibility for proceeding based on the ability to obtain sufficient past medical, behavioural and social history.
- 8.4 On the rare occasion where the patient has consented and the person who is ranked highest in the qualifying relationships declines the option of donation, an agreed position should be reached by inclusive discussion with the family/next of kin, ICU Consultant and Donor Transplant Coordinator. The Family should be encouraged to accept the wishes of the deceased and it should be made clear that they have no legal right to veto those wishes. There may, of course, be situations in which donation is inappropriate and each family should be considered individually.
- 8.5 The following list represents the relationships in descending order that should be involved in the discussions². The person ranked highest in the list should be identified and consent sought.
- Spouse or partner (including civil or same sex partner)
 - Parent or child
 - Brother or sister
 - Grandparent or grandchild

- Niece or nephew
 - Stepfather or stepmother
 - Half brother or half sister
 - Friend of longstanding
- 8.6 In the case of a child (<18 yrs) who has registered on the NHS Organ Donor Register, it is the responsibility of the Donor Transplant Coordinator to discuss with those who have parental responsibility for the child and take their views into consideration before deciding how to proceed. Enquiries should be made as to the competence of the child at the time of registering.
- 8.7 In the absence of someone with parental responsibility i.e. in the case where they died at the same time as the child, responsibility is passed to the next person who has highest ranking in the qualifying relationships.

Where there is no record of the patient having registered on the NHS Organ Donor Register

- 8.8 In the absence of a signed donor card or registration on the NHS Organ Donor Register, the Donor Transplant Coordinator will enquire whether the patient had nominated a representative to make decisions on their behalf.
- 8.9 In the absence of a nominated representative the person with the highest ranking qualifying relationship will be consulted enquiring as to whether the patient had ever expressed a wish to donate in his/her lifetime.
- 8.10 Where there are no nominated representatives, family/next of kin or friends traceable and in the absence of any known wishes of the individual donation cannot proceed.
- 8.11 In the case of a child <18 years of age who has not registered on the NHS Organ Donor Register, consent must be obtained from the person with parental responsibility. Where there are 2 individuals with equal responsibility, consent must be obtained from one.

Documenting consent

- 8.12 It is the responsibility of the Donor Transplant Coordinator to obtain a signature from the nominated representative or qualifying person to confirm their consent¹¹ having first provided information on the donation process¹². A copy of the consent together with a detailed

¹¹ UK Transplant 2007 FRM/MED/CM.032/02 Consent – Organ & Tissue donation

¹² UK Transplant 2007 MPD/MED/CM/051/03 management description process document

description of the discussions undertaken should be filed in the patient's medical notes.

- 8.13 In situations where they are unable to sign e.g. living abroad or communicating via the telephone it is acceptable for the donor Transplant Coordinator who is taken the consent to document the details in the patient's notes. A second person should be available to listen to the Donor Coordinators conversation and sign to confirm they have witnessed this and where possible the conversation will be taped¹⁰.
- 8.14 The Donor Transplant Coordinator will also establish a detailed medical, surgical and social history of the potential donor. It must also be explained that a sample of blood is taken from the potential donor for virology testing¹³. This is done to minimise the risk of transmission of any infections and/or diseases to the transplant recipient.
- 8.15 Should the patient's organs or tissues prove unsuitable for transplantation having been retrieved for this purpose, consent will have been sought during the consent process by the Donor Transplant Coordinator with regard to research and disposal options^{2,12}.
- 8.16 If the family do not wish for specific organs and tissues to be used for research purposes, they are informed that these tissues will be respectfully disposed of².

9. Obtaining Coroners consent

- 9.1 It is the responsibility of the ICU Consultant or designates to report the death, where necessary, to the Coroner. Advice on which deaths should be reported can be found on the BSUH intranet (supporting patient care/bereavement services/when to contact the coroner). All deaths < 18 yrs must be reported. See BSUH Intranet (supporting patient care/bereavement services/RAC – end of life and bereavement policies)
- 9.2 It is the responsibility of the Donor Transplant Coordinator to obtain consent from the Coroner before organ and/or tissue donation can proceed.
- 9.3 The Coroners decision must be documented clearly in the patient's medical/nursing notes by the ICU medical staff or Donor Transplant Coordinator.
- 9.4 Prompt reporting of the death by medical staff is essential to ensure minimal delay in the retrieval process and the added anxiety this can

¹³ Department of Health 2000. 'Guidance on the Microbiological Safety of Human Organs, Tissues and Cells used in Transplantation'

bring to families. The Donor Transplant Coordinator may approach the Coroner on behalf of the senior medical staff, if required once the death has been reported.

- 9.5 The Coroner can be contacted by telephoning the appropriate coroner's office depending on the location of the death.

Brighton 01273 66525/6
Haywards Heath 01444 445808.
Out of hours 0845 6070999 (ask for the coroners officer giving the location of the death)

- 9.6 If a Coroner's investigation is **not** required, then the patient's Death certificate can be issued directly to the family by the Bereavement services. See BSUH Intranet (supporting patient care/bereavement services/bereavement policy TCP200)

Having established consent from the family and the Coroner there are 2 different pathways depending on whether it is donation after brain stem death or donation after cardiac death. The following section refers to donation after brain stem death.

10. Donation after Brain Stem Death

Supporting the brain stem dead donor in ICU

- 10.1 Having established consent for donation it is the responsibility of the ICU Consultant, the Donor Transplant Coordinator and those caring for the deceased to optimise organ perfusion in accordance with the Intensive Care Society Guidelines on the clinical management of the potential heart beating organ donor³. See BSUH Intranet (supporting patient care/critical care/intensive care/organ donation/intensive care guidelines)

Arranging the retrieval operation

- 10.2 In the context of established consent, the Coroner approval and acceptance by transplant teams, it is the responsibility of the Donor Transplant Coordinator to contact the person in charge for theatres to discuss a proposed theatre time. This should be based on the availability of operating theatre space, support staff in theatre, on call anaesthetic cover and the availability of visiting transplant teams.
- 10.3 It will be the responsibility of the person in charge of theatres to contact the on call anaesthetist to inform of the pending retrieval.
- 10.4 In all cases of donation after brain stem death there will be a requirement for an on call anaesthetist to be available. On rare occasions where there is a visiting cardiothoracic transplant team

attending there may be a physiologist present who can provide airway maintenance however this cannot be guaranteed.

- 10.5 If cardiothoracic organs are considered unsuitable prior to the retrieval commencing the visiting team will not stay and hence an anaesthetist is required to support the liver transplant team.
- 10.6 A member of theatre staff will be required to help support visiting organ retrieval teams with local orientation to equipment and procedures and to ensure that additional equipment i.e. suction is readily available.
- 10.7 The Donor Transplant Coordinator will liaise directly with the on call anaesthetist and the person in charge of theatres regarding confirmation of retrieval times and needs of surgical teams.
 - Equipment required in theatre are
 - Operating table
 - ECG, CVP and arterial blood pressure monitoring
 - Anaesthetic machine
 - 3 or 4 bowl stands
 - 4 drip stands and 3 trolleys
 - Diathermy
 - 2 suction units
 - 8 suction liners
 - Last offices pack

The retrieval operation

- 10.8 Once the visiting transplant teams have arrived and prepared in theatre it will be the responsibility of the Donor Transplant Coordinator, the on call anaesthetist and ICU nurse caring for the deceased to prepare and transfer them to the operating theatre.
- 10.9 Once in theatre it will be the responsibility of the on call anaesthetist to ensure the safety of the deceased prior to the retrieval commencing
- 10.10 It is the responsibility of the visiting transplant teams to communicate with all persons involved in the retrieval process, check the deceased's medical notes for confirmation of brain stem death, consent, blood group and assessment of risk factors with the general suitability of the donor and check the deceased's identification against the patient's identification band.
- 10.11 In cases of cardiothoracic retrieval the visiting transplant team may carry out investigations and insert monitoring prior to the retrieval commencing to assess suitability i.e. bronchoscopy and/or echocardiogram. On occasions these investigations may indicate unsuitability for retrieval and the visiting cardiothoracic team will depart leaving the abdominal retrieval team to commence.

- 10.12 The visiting surgeon should communicate with the on call anaesthetist about the stability and haemodynamic data, blood gases/Fio₂, lung compliance, amount of tracheal suction, blood results, inotropic support and blood loss and colloid replacement. As instructed from the surgical team, the anaesthetist will administer to the donor prophylactic antibiotics and Methyl prednisolone and collect blood for sampling when directed.¹⁴
- 10.13 The Donor Transplant Coordinator will be present throughout the retrieval operation to ensure the patient's dignity and respect is maintained throughout and to ensure the smooth running of the retrieval process. This will include supporting a member of the theatre team in ensuring additional equipment i.e. suction is available and working effectively.
- 10.14 It is the responsibility of the theatre staff to ensure that local theatre policies are adhered to and appropriate local documentation is completed for theatre records
- 10.15 Once the organs have been removed the incision is sutured by the retrieval teams and a dressing applied by the Donor Transplant Coordinator when carrying out last offices.
- 10.16 It is the responsibility of the visiting transplant teams to ensure they have documented the outcome in the patient's medical notes and completed the appropriate organ transplant documentation.
- 10.17 It is the responsibility of the Donor Transplant Coordinator and theatre staff to perform last offices and carry out any requests the family may have made i.e. hand prints and/or locks of hair.
- 10.18 Where the family have requested to view the deceased following donation this should be arranged jointly by the Donor Transplant Coordinator and theatre staff identifying an appropriate area to facilitate this.
- 10.19 Where families have left the hospital it is the responsibility of the Donor Transplant Coordinator to maintain communication as previously discussed and agreed prior to the retrieval¹⁵
- 10.20 It is the responsibility of the theatre staff to ensure the deceased is transferred to the mortuary as per hospital policy (intranet/supporting patient care/bereavement services/bereavement policy)

¹⁴ **UK Transplant 2005** Donor retrieval process for hearts and lungs. www.uktransplant.org.uk

¹⁵ **UK Transplant 2004** Donor Family Care Policy. www.uktransplant.org.uk

10.21 Where consent has been given for tissue donation, arrangements will be made by the Donor Transplant Coordinator for this to be retrieved in the mortuary the following day (see 13 tissue donation)

11. Organ donation following cardiac death

11.1 In the situation where an individual has suffered a catastrophic neurological injury and the decision has been made to withdraw treatment, donation after cardiac death may be possible. Contact should be made with the Donor Transplant Coordinators to discuss suitability. In these cases death has not occurred and the patient should be placed on the Liverpool care pathway for critical care , commencing section 1, goals 1-3.

11.2 The Donor Transplant Coordinator will check the NHS Organ Donor Register. Where there is evidence of the individuals wish and/or the request from the patient's family/next of kin to consider organ donation, the Donor Transplant Coordinator and ICU Consultant will agree a plan to discuss donation when goal 4 is reached in the Liverpool Care Pathway for critical care (see 7 & 8).

11.3 Suitability will depend on the patients past medical, social and behavioural history, current clinical status, the level of support currently required to maintain stability i.e. oxygen and inotrope requirements, the clinicians proposed method of withdrawal and the level of spontaneous respiratory effort. All of which require an on site assessment by the Donor Transplant Coordinator to make a decision as to whether donation should be raised.

11.4 It is the responsibility of the Donor Transplant Coordinator to establish and document consent (see 8.12-16)

11.5 Contact with the Coroner should be made prior to the withdrawal of treatment and death as minimising any time delays once death has been confirmed is crucial. (see 9.5)

11.6 In the presence of established consent and the Coroner approval the timing of withdrawal of treatment (Goal 7 Liverpool Care Pathway for critical care) is delayed to allow for mobilisation of retrieval teams and theatre suitability.

Withdrawing treatment and the retrieval operation

11.7 Treatment is withdrawn either in the ICU or the anaesthetic room. The decision will be made by inclusive discussion taking into account patient's dignity and family's needs.

11.8 Once the transplant teams have arrived and are prepared in theatre then withdrawal of treatment can occur. It is the responsibility of the Donor Transplant Coordinator to confirm time for withdrawal.

- 11.9 At this point goal 7 of the Liverpool Care Pathway for critical care should be completed with the exception of maintaining electronic monitoring. The Donor Transplant Coordinator will be responsible for monitoring the patient's cardiovascular status until asystole is reached or the decision to abandon donation reached.
- 11.10 Immediately prior to withdrawal of treatment nursing staff should transfer all monitoring to a portable screen and all electrical leads to infusion devices disconnected. There should be nothing attached to the patient/bed that may cause a delay to transfer after death
- 11.11 The process of withdrawal should be determined according to current ICU end of life practices.
- 11.12 At this point section 2 of the Liverpool Care Pathway for critical care should be completed
- 11.13 It is the responsibility of the ICU Consultant or their designate to remain throughout the withdrawal period until asystole occurs and to certify death following a 5 minute period of asystole.
- 11.14 If the dying process is delayed (beyond 3 hours) the decision to abandon organ donation will lie with the visiting transplant surgical team. Liver and lung donation is possible up to 1 hour after asystole occurs. Kidney and pancreas donation is possible up to 3 hours after asystole.
- 11.15 Once certification of death has been completed, a further 5 minutes with no interventions may be observed to allow the family time to say their goodbyes.
- 11.16 10 minutes after asystole occurs, the patient is immediately transferred to the operating theatre and awaiting transplant surgeons
- 11.17 If no family is present then the patient can be moved directly to the operating theatre after pronouncement of death.
- 11.18 It is the Donor Transplant Coordinator, ICU Consultant or their designate and nursing staff responsibility to support the family during this process whilst maintaining the respect and dignity of the patient throughout the procedure.
- 11.19 Once in theatre the patient will be transferred to the operating table and a rapid incision is performed to establish cannulation of the major vessels in order to commence the preservation and cooling process. Once preservation is established the surgical retrieval is performed and the process follows that of the retrieval for donation after brain stem death (see. 10.14-22)

12. POST-ORGAN DONATION

- 12.1 In all cases of organ donation the Donor Transplant Coordinator will write to the donor family within 14 days post-donation, to inform them of the outcome of the organ/tissue donation, as well as to thank them for their decision. Family support is available directly by the Donor Transplant Coordinator who will refer families to specific community bereavement services and organ donor family support groups.
- 12.2 The Donor Transplant Coordinator will contact the healthcare professionals involved with the organ donation to inform them of the outcome of the donation & the transplant recipient's progress, and to thank them for all their help/support.
- 12.3 The Donor Transplant Coordinator will provide follow up information and support to all staff involved post donation. This should be within 7 days of the donation.

13. TISSUE DONATION

Responsibility of staff caring directly for patients and their families at the point of death

- 13.1 All families should be offered information on the option of tissue donation and staff should explore any known wishes of the deceased regarding donation before the family leave the hospital. Tissue donation is only possible within 24 hours after death.
- 13.2 The NHS Organ Donor Register should be checked to ascertain any known wishes of the deceased.
- 13.3 **The NHS Organ Donor Register can be accessed by any healthcare professional working from a hospital by telephoning 0117 9757575.** They will ask for the patient's name, their date of birth and post code and the callers name, department and hospital switchboard number. Having checked the register they will return the call via switchboard.
- 13.4 Whilst waiting for the outcome of the NHS Organ Donor Register, check the patient has none of the following general contraindications
- **Infectious diseases** i.e. CJD, HIV, Hep A, B & C, (inc behaviour relating to an increased risk), Tuberculosis (MRSA is not a contraindication for corneal donation)
 - **viral disease** i.e. viral meningitis (bacterial sepsis or meningitis is acceptable)
 - **central nervous system diseases** of unknown aetiology (e.g., Alzheimer's disease or other dementias, Parkinson's disease, Multiple Sclerosis, Motor Neurone disease)
 - **Malignancies** (leukaemia, lymphoma, myeloma, sideroblastic anaemia, polycythaemia) **Solid organ malignancy is NOT a contraindication for corneas**

- **Auto immune diseases** i.e. sarcoidosis, rheumatoid arthritis, crohn's disease
- **Previous organ transplant**

13.5 If staff are unsure of the suitability for tissue donation, contact can be made to the East Grinstead eye bank (available 24 hours a day). Advice will be offered as to their suitability **Telephone East Grinstead Hospital switchboard 01342 414000 and ask to page the on call eye retriever.**

Patient registered on NHS Organ Donor Register

- 13.6 If the patient is registered for all organs and tissues, organ donation being unsuitable in this case, this indicates their consent for corneal donation and possible support for other tissues i.e. skin, bone and heart valves. Whilst other tissues are not listed separately on the registration these options will be discussed with the family/Next of kin by the on call tissue coordinator if appropriate.
- 13.7 If the patient has a history or current diagnosis consistent with the contraindications, tissue donation is not possible. Document in the patient's notes that they are on the NHS Organ Donor Register but unable to donate
- 13.8 During the post death meeting explain to the family you are unable to offer the option of tissue donation and explain the reason why.
- 13.9 Where there is no contraindication present, inform the family/Next of kin that the patient is registered on the NHS Organ Donor Register. Ask if they are supportive of the patient's wishes.
- 13.10 Where the family/Next of kin are supportive of donation, document the conversation clearly in the patient's notes and inform them that they will be contacted by a specialist in tissue donation within a few hours or the following day if the death occurred at night. Identify the appropriate telephone number where the family/NOK will be to receive the call.
- 13.11 If the family/Next of kin decide not to support the patient's wish, document this in the patient's notes. Advise them that if they change their mind to call back to the department with 12 hours for donation to be considered.
- 13.12 Having documented the conversations and completed the post death meeting the family/Next of kin can leave on the understanding they will be contacted in due course.

Patient not registered on the NHS Organ Donor Register

- 13.13 Many people support donation but may not register their wishes on the NHS Organ Donor Register. If the patient is not registered the person carrying out the post death meeting should still consider donation and check suitability against the general contraindications (see 13.4)
- 13.14 The nurse conducting the post death meeting with the family should enquire as to whether the deceased had expressed a wish to donate after their death. The BSUH NHS Trust tissue donation leaflet should be given to all families alongside the bereavement information on how to register a death. The leaflet

should be used as a prompt to raising a discussion about any known wishes the deceased may have had.

Suggested opening statements to the donation discussion are; ***“I am very aware that many people have considered donating organs and tissues after their death. In your (relative’s) case tissue donation may be an option but I would have to make some enquiries. I am raising this at this time because this is only possible within 24 hours after their death. Is this something you recall talking about?”***

“ I am very willing to make some enquiries to see if anything is possible on your behalf.”

“ This leaflet explains a little more, please get back to me if I can help”.

- 13.15 Where the family/Next of kin are supportive of donation document the discussion in the patients medical notes (see 13.10)
- 13.16 If more information is requested staff can contact the on call tissue retrieval staff at the East Grinstead eye bank (see 13.5) for advice.
- 13.17 In the case of the family being unsure or wishing to think about it, highlight the time frame of a maximum of 24 hours in which to be able to retrieve tissue and hence the need to confirm within 12 hours in order to successfully retrieve tissue.
- 13.18 Where there it is a requirement to inform the coroner of the patient’s death, it is the responsibility of the medical doctor to do this immediately after the death to allow the coroners permission to be sought within the allotted time frame.
- 13.19 The Coroner can be contacted by telephoning the appropriate coroner’s office depending on the location of the death
- **Brighton 01273 66525/6**
 - **Haywards Heath 01444 445808.**
 - **Out of hours 0845 6070999 (ask for the coroners officer giving the location of the death)**
- 13.20 Where the death has occurred between 08.00 and 16.00 the coroner’s officer can be contacted in the appropriate office. Messages can be left but will only be picked up between the above hours on weekdays
- 13.21 Where the death has occurred after 16.00 or during the night, and the following day is a normal working weekday, a message can be left on the answer phone of the appropriate Coroner’s Officer to warn of tissue donation request. The formal referral to the Coroner must be made as early as possible the following day taking into account the time elapsed from the time of death.
- 13.22 If the following day is a weekend or Bank Holiday then contact should be made as soon as possible out of hours through the Police.
- 13.23 Where there is support for donation and agreement from the family/Next of kin to proceed and this has been documented in the patient’s medical notes

staff should contact the on call tissue coordinator at the East Grinstead Eye Bank to formally refer the case. (**Telephone East Grinstead Hospital switchboard 01342 414000 and ask to page the on call eye retriever. Available 24 hours**)

- 13.24 Ensure the notes and contact details for the family/Next of kin are available when telephoning
- 13.25 The tissue coordinator will require information on the patient's past medical history, cause of death if known, GP details, contact numbers of family/Next of kin
- 13.26 It is essential that the referral call is made by the nurse who has knowledge of the patient and their family and should be made as soon as possible after the family have left the hospital and always before the end of their shift. Avoid handing the responsibility over to a second person
- 13.27 Ensure the date and time of the referral call is documented in the patient's notes.
- 13.28 It is essential that there is clear documentation stating all conversations held with the family, and coroner if appropriate. Good communication with mortuary staff is vital to achieving a successful tissue donation
- 13.29 It is the responsibility of the On Call tissue coordinator to contact the patient's family/Next of kin to discuss the options of donation and gain the families consent for tissue donation. The family will receive a telephone call from the on call tissue coordinator having received the coroners consent. This is a recorded telephone consent process
- 13.30 In cases where donation is not possible the family will be informed by the on call tissue coordinator
- 13.31 The on call tissue coordinator will organise the tissue retrieval process with assistance from the relevant Tissue banks. This process is carried out in the mortuary and does not delay movement of the patient from the ward area or the ability to view the deceased. For advice on viewing see BSUH intranet (supporting patient care/bereavement services/arranging a viewing)
- 13.32 All staff are responsible in ensuring the deceased is treated with dignity and respect throughout the tissue retrieval process

The tissue retrieval – responsibilities of staff working in the mortuary

- 13.33 Having obtained consent from the family/Next of kin and agreement from the Coroner, it is the responsibility of the on call tissue coordinator to contact the mortuary staff and make arrangements for a convenient time to carry out the retrieval
- 13.34 It is the responsibility of the mortuary staff to ensure they have documented evidence in the patient's notes or the relatives' wishes regarding tissue donation. A copy of the consent can be obtained by fax from the on call tissue coordinator

- 13.35 If access is required to the mortuary out of hours the on call mortician will be contacted to make arrangements.
- 13.36 2 people must separately check the patient's identity band and referral details for name, hospital number and date of birth before tissue retrieval can take place.
- 13.37 It is the responsibility of the visiting tissue retrievers attending the hospital site to be satisfied that consent has been given by the family prior to retrieving tissue.
- 13.38 If the pathologist or mortuary staff are required to retrieve tissue on behalf of the tissue banks (heart valves), they must ensure that they have received a fax from the on call tissue coordinator to confirm consent from the family. This should be filed in the patient's notes following the retrieval.
- 13.39 Any concerns regarding a deceased in the mortuary who has undergone organ and/or tissue retrieval should be made directly to the Donation Nurse Specialist (telephone 0778 7530926)
- 13.40 All tissue retrieval activity should be documented in a log and kept within the mortuary for future reference.
- 13.41 All families are spoken to by the on call tissue coordinator at the time of consent. It is not possible to offer a service of follow up letters to staff however the Donor Nurse Specialist is responsible for auditing donation activity which includes tissue donation outcomes. Feedback is available on request

Requests for donation made through Bereavement Services

- 13.42 All requests for donation from families who attend the Bereavement office following a death within 24 hours of the death should be passed onto the East Grinstead eye bank for consideration of tissue donation.
- 13.43 All requests for donation from families exceeding the 24 hour time frame for tissue donation to be recorded by bereavement staff and Donation Nurse Specialist informed for follow up.
- 13.44 In some circumstances where the 24 hour period has been exceeded it may be possible to retrieve tissues for the sole purpose of research as opposed to transplantation. In such cases advice should be sought from the East Grinstead eye bank.
- 13.45 All enquiries with regard to an existing donation request should be passed onto the Donor Transplant Coordinator if relating to solid organ donation from ICU or East Grinstead Eye bank if relating to tissue donation.

14. Monitoring organ donation standards

- 14.1 It is a requirement that all NHS Trusts should have a donation committee that monitors donation practice and reports directly to the Trust board¹. The BSUH Trust Donation committee meets quarterly. It's terms of reference are to;

- Influence policy and practice in order to ensure that organ donation is considered in all appropriate situations and to identify and resolve any obstacles to this.
 - To ensure that a discussion about donation features in all end of life care, wherever located and wherever appropriate, recognising and respecting the wishes of individuals.
 - To maximise the overall number of organs donated through better support to potential donors and their families.
- 14.2 The Donation Nurse Specialist is responsible for collecting data on all deaths that occur in ICU as part of the national UK Transplant Potential Donor Audit¹⁶. This data is then reported to the Donation committee for review against NHS performance indicators and to the ICU Clinical Governance group quarterly
- 14.3 The Clinical lead for organ donation is responsible for reporting donation activity to the Chief Executive who in turn reports to the Trust board.
- 14.4 The donation Nurse Specialist is responsible for meeting the educational needs of staff directly involved in organ and tissue donation.

¹⁶ UK Transplant 2003 Potential Donor Audit www.uktransplant.org.uk

Appendix 1

Glossary of terms

ASYSTOLE	Is the cessation of an effective heart beat and spontaneous respiratory effort.
BRAIN STEM	Is the important site in the human brain responsible for maintaining breathing, heart rate, blood pressure, and level of consciousness. The brain stem connects the spinal cord to the brain, and relays all vital information between the body and the brain.
BRAIN STEM DEATH	'Is the irreversible loss of the capacity for consciousness combined with irreversible loss of the capacity to breathe' (DOH, 1998) This is considered to be incompatible with life and therefore death is diagnosed
DONOR FAMILY	The term donor family is used generically to refer to the family and friends of longstanding. For the purposes of obtaining consent this must include the nominated representative or in their absence the person in the highest qualifying relationship.
DTC	Donor Transplant Coordinator. A regional specialist in donor care responsible for responding to all organ donation referrals and maintaining a 24 hour on call procurement service
DNS	Donation Nurse Specialist, A specialist in donor care working locally within the ICU responsible for leading donation practice providing advice, support and education on all donation issues
HUMAN TISSUE ACT	The Human Tissue Act 2004 implemented 1 st September 2006 which extends to England, Wales and Northern Ireland. The Human Tissue Act repeals and replaces the Human Tissue Act 1961, the Anatomy Act 1984 and the Human Organ Transplants Act 1989
HUMAN TISSUE AUTHORITY	The Human Tissue Act 2004 establishes the Human Tissue Authority to act as the regulating body for all matters concerning the donation of organs and tissues for transplantation
NOMINATED REPRESENTATIVE	Adults may nominate one or more people to represent them after death over the issue of consent for the removal, storage and use of organs and tissues for transplantation. A nominated representative may be appointed orally in the presence of two witnesses or in writing with a witness attesting the signature. A

nominated representative will take precedence over a person in a qualifying relationship

NHS ODR

The NHS Organ Donor Register is a confidential computerised database managed by UK Transplant which holds details of people who have signed up to become organ donors in the event of their death

QUALIFYING RELATIONSHIP

In the absence of a nominated representative, the Human Tissue Act 2004 ranks persons in a qualifying relationship for the purpose of obtaining consent.

- a. Spouse or partner (including civil or same sex partner)
- b. Parent or child
- c. Brother or sister
- d. Grandparent or grandchild
- e. Niece or nephew
- f. Stepfather or stepmother
- g. Half brother or half sister
- h. Friend of longstanding

The ranking is intended to help those seeking consent to know who to approach. Consent should be obtained from the person in the highest ranking qualifying relationship.

TISSUE COORDINATOR

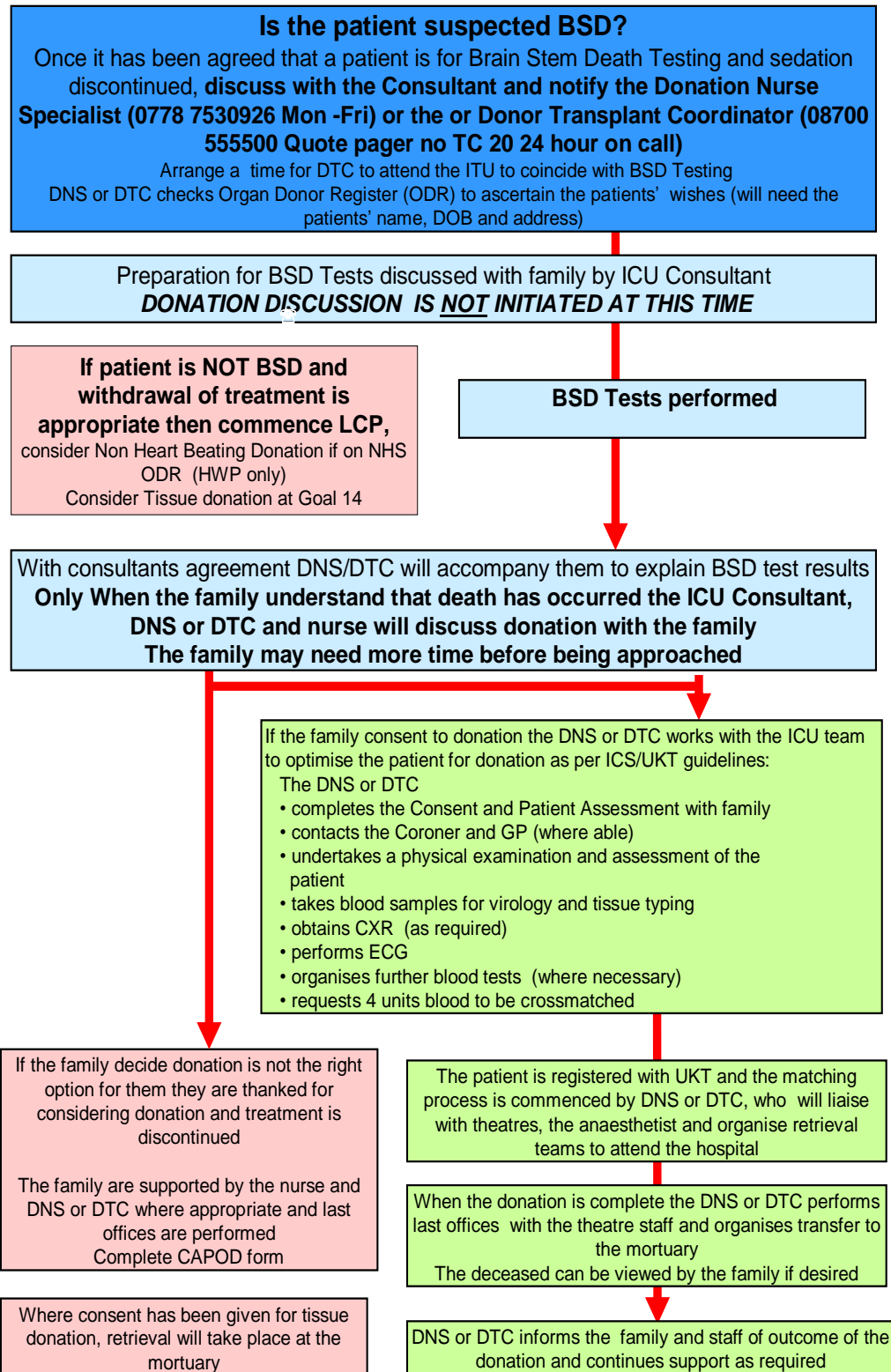
An on call specialist responsible for gaining consent and coordinating the retrieval of tissue for transplantation. They may be employed by the East Grinstead Eye Bank or Tissue Services. Both follow strict operating procedures in accordance with the Human Tissue Authority

UK TRANSPLANT

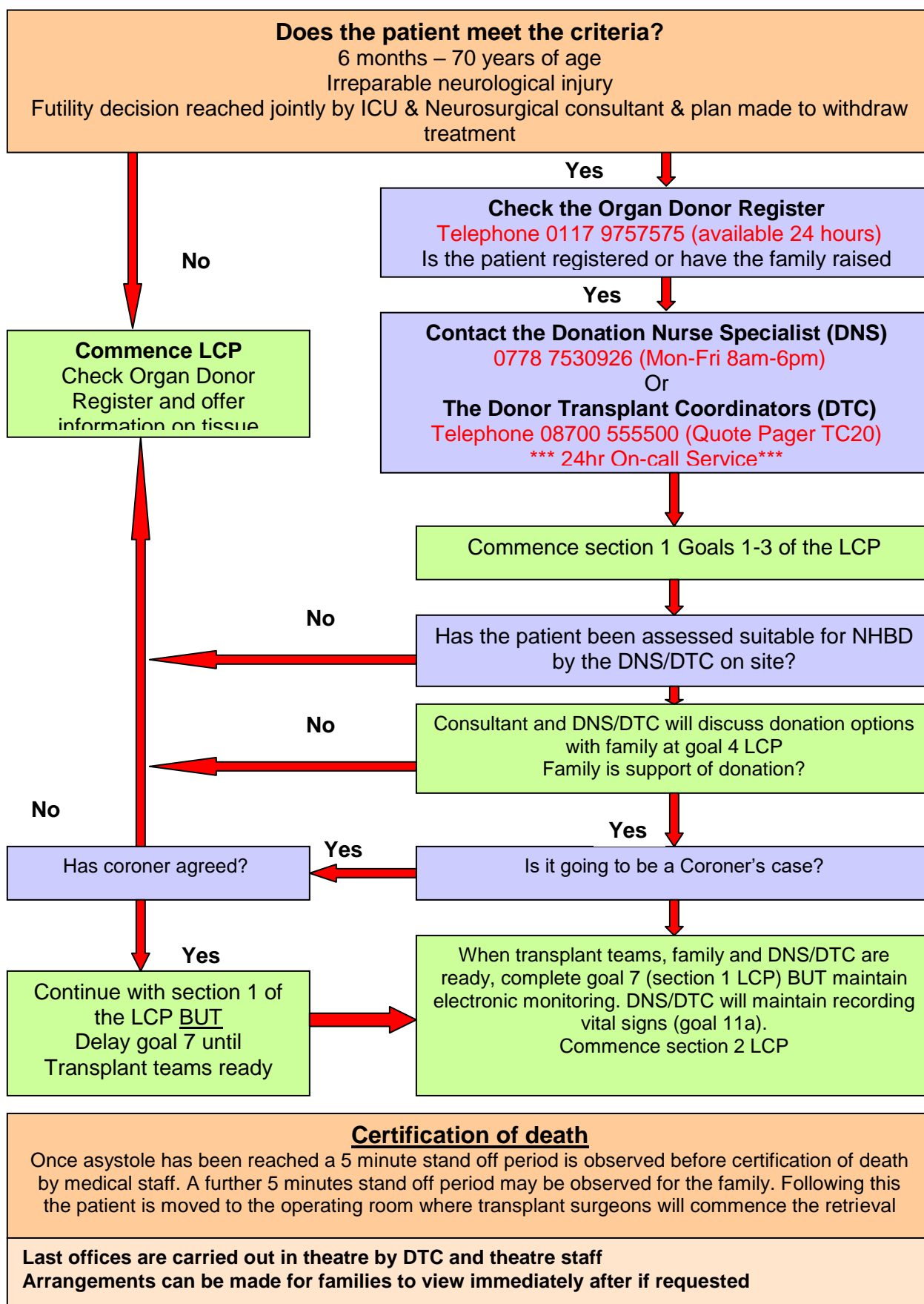
UK Transplant is part of NHS Blood and Transplant a special Health Authority within the NHS responsible for managing the National Blood Service, Bio Products Library and UK Transplant. UK Transplant is responsible for maintaining the National Organ Donor Register and managing the National Database which includes details of all donors and patients who are waiting for, or who have received a transplant. UK Transplant is responsible for auditing and analysing the results of organ donation & transplantation in the UK and Republic of Ireland to improve patient care.

Appendix 2

ORGAN DONATION AFTER BRAIN STEM DEATH Notification to Donor Transplant Coordinator and family approach



Donation after cardiac death (PRH & HWP only)



Appendix 4

TISSUE DONATION

DEATH (Wards, ITU, A&E)

