

The following presentation was prepared as part of the NHS South Central End of Life Care programme. The aim of this presentation is to inform those individuals who are providing End of Life Care about the need to discuss Organ and Tissue Donation as part of Advance Care planning (ACP). The presentation offers information, guidance and support regarding the process of Organ and Tissue Donation, and what you as a care provider need to do to refer a potential donor to the relevant service.

The presentation is aimed at individuals working in hospital, hospice, residential, and community care areas, however the information it contains may be of interest to a wider audience as a means of raising awareness regarding the option of Organ and Tissue Donation.

The issue of Organ and Tissue Donation needs to be considered early on as a part of ACP and this presentation will explore this. It is essential that those individuals who chose to **alert** families to this option have the necessary knowledge of where to refer potential donors and family members to, this presentation provides this guidance; however this presentation is not sufficient preparation to **make the request** for Organ or Tissue Donation, this must be done by the services indicated in these slides.

Organ and Tissue Donation

As part of End of Life Care

The importance of Advance Care Planning [ACP]

- It is important that people are given the opportunity to express their wishes about their end of life care so that these can be discussed with their family and care provider. Discussing preferences such as preferred place of death, wishes regarding resuscitation, or Organ and Tissue Donation overcome misunderstandings and facilitates the fulfilling of people's wishes when they are dying and, after their death.
- It is important therefore to support your patients/residents/family members by offering them the opportunity to Advance Care Plan as early as is appropriate for them (for more details see the Advance Care Plan Toolkit at <http://www.southcentral.nhs.uk/what-we-are-doing/end-of-life-care>).

Organ Donation

Three people a day die in need of a transplant due to low donation rates.

Research indicates that low donation rates are linked to multiple factors. Two that you can influence are:

- Family members saying no to donation after the death of their family member because they are unaware of the deceased wishes regarding donation.
- Care providers being reluctant to raise the issue of donation with family members as they are fearful of causing distress.

Research indicates that:

- The majority of people are in favour of donation regardless of ethnicity or religious preference [YouGov, 2007]
- Family members are not distressed by being asked about donation, they value the opportunity to consider this option [Sque et al, 2003]

Who can donate?

- There are specific criteria to be met as the following slides will illustrate.
- Guidance and support is only a telephone call away.

Donation after Brain Death (DBD)

- Potential donors are usually patients in critical care areas
- Death is confirmed by Brain Stem Death (BSD) testing.
- No upper age limit.
- Only absolute contraindication is CJD.
- A Coroner's consent may be required prior to donation.
- Potential organs for donation include: Heart, Lungs, Liver, Kidneys, Pancreas, Small Bowel.
- Tissue donation is also possible.

Donation after Circulatory Death (DCD)

- Potential donors are usually in critical care areas and are undergoing a planned withdrawal of treatment.
- Death is confirmed using cardio respiratory criteria.
- Retrieval teams set up in theatre prior to withdrawal of treatment.
- Potential organs for donation include: Lungs, Liver, Kidneys, Pancreas.
- Tissue donation is also possible.

When to refer to the Organ Donation Service?

Before Brain Stem Death testing is performed

OR

After decision has been made to withdraw treatment

Remember

- The Organ Donor Register should be checked before family are approached about donation
- The Specialist Nurse in Organ Donation [SN-OD] should be involved in any approach to the family
- A Specialist Nurse **must** take consent for organ donation.

How to check the Organ Donor Register?

- Call **0117 975 7580** (24hrs) – ask to check the Organ Donor Register.
- You will need the patients name, date of birth and address.
- If a patient is registered, you will be told when they registered and what they have consented to donate.

How to refer a potential Organ Donor?

- Page the on call Specialist Nurse on **07659 183 499**.
- Leave your name, name of hospital and a telephone number on which **you** can be contacted.
- A Specialist Nurse will return your call within 20 minutes.

Tissue Donation

One tissue donor can enhance the lives of 50 people.

Who can donate?

- Almost everybody can be considered for tissue donation after death.
- There are specific upper and lower age limits for some tissues [seek advice from Tissue Services].
- There is no upper age limit for eye donation.
- A Coroner's consent may be needed for tissue donation

What Tissues can be donated?

- Eyes
- Heart Valves
- Skin
- Bone
- Tendons

General contraindications for Tissue Donation:

- Systemic infection
- HIV, Hepatitis B or C
- Dementia and other neuro-degenerative diseases
- Diseases of unknown aetiology
- Leukaemia and Lymphoma
- Patients diagnosed with Cancer who do not have ocular involvement are able to donate eyes.

Essential information:

- Eye donation **must** take place within 24 hours
- The potential eye only donor does not need to be in a mortuary for donation to take place, but arranging eye donation outside of hospital settings is difficult [discuss with NHSBT Tissue Services].
- Other tissue can be donated up to 48 hours after death
- If multi tissue donation is to take place the donor **must** be in the mortuary within 6 hours of asystole
- In **all cases** a blood sample from the potential donor is needed by the retrieval team within 24 hours of death.

Talking to families about Tissue Donation

A part of End of Life Care

Alerting families to the potential of Tissue Donation:

- Raise the possibility of tissue donation at the time you are giving family members information on what to do next i.e. when to contact Bereavement Care or how to register the death.
- Bring their attention to the tissue donation leaflet within your Bereavement Booklet.
- Explain that someone from NHSBT Tissue Services can explain what happens.
- Remember the worst has already happened and by alerting families to the potential of tissue donation you are giving them a choice – which may provide comfort to them in the future [Sque et al, 2005].

What you might say:

- Every family is different and you must use your judgement in alerting families.
- For example you might say “Mrs Jones could I just mention that your husband is able to donate tissue for transplant operations. Donation of tissue can enhance the quality of other people’s lives such as restoring someone’s sight. There is information about tissue donation in this leaflet, and a Nurse Practitioner from tissue services can contact you at home to discuss in more detail. Is that ok?”

How to refer a potential Tissue Donor?

- To refer a potential tissue donor, or to gain advice regarding whether a patient is a potential tissue donor, call the National Referral Centre on **0800 4320559**
- Leave your name, the name of the hospital, hospice, care home where you are ringing from, and a telephone number on which someone is available who can answer questions about the deceased.
- If you refer a patient between the hours of **8 am - 9 pm** a nurse practitioner will call you back within 20 minutes.
- If you refer a patient between **9pm - 8am** details will be taken and a nurse practitioner will call you back after 8 am.

What happens next?

The Nurse Practitioner at NHSBT Tissue Services will ensure that:

- The approach to the family is made in a sensitive manner
[Beaulieu, 1999; Siminoff et al, 2001; Sque et al, 2005]
- Information is delivered in a manner that assists the family in understanding what is required.
[Long, 2007; Verble and Worth 1999; Long et al, 2006; Kent, 2007]
- Information is sufficient in both quality and quantity
[Verble and Worth, 1999; Long et al, 2006]

What happens after Tissue Donation?

- Family members receive letters of thanks from NHSBT Tissue Services.
- Letters indicate whether donation took place, and how donated tissues were used.
- Limited information about the recipient are provided to family members of the deceased, if they wish to receive it.
- Information regarding the outcome of donation is available to family members.
- Families are offered follow up and a link to Bereavement Services if they wish.

**Please consider raising the issue of
Organ and Tissue Donation as part of
your End of Life Care.**

**Help and guidance is only a phone call
away.**

Contact details and training links:

Advance Care Planning

- For further information about advance care planning visit <http://www.southcentral.nhs.uk/what-we-are-doing/end-of-life-care/> where you will find an ACP toolkit, this also provides details of the training available to help staff support people in advance care planning including communication skills.

Tissue Donation

- National Referral Centre on **0800 4320559**

Organ Donation

- Page the on call Specialist Nurse on **07659 183 499**

Organ Donor Register

- Call **0117 975 7580**

References:

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