



Child and
Young Person's
Advance Care Plan
Collaborative

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Organ and Tissue Donation Supporting Guidance for Professionals

Everyone has a choice as to whether they want to or not become an organ and/or tissue donor after they die. Decisions regarding organ and tissue donation can directly impact care at or around end of life and form an integral part of advance care planning discussions.

These discussions are largely supported by patients, families and healthcare professionals, though in practice are often avoided or delayed. We aim to provide clear information to support understanding of the benefits and importance of addressing this sensitively and early in the planning process.

What is Organ Donation?

Organ Donation is the donation of solid organs such as heart, lungs, liver, kidneys, pancreas and small bowel for life saving transplant procedures. Some organs can be donated whilst you are alive, a process known as living donation. Most organs, however, are donated after a person has died. To donate organs after death, a person needs to die in hospital in specific circumstances. Specialist Healthcare Professionals will assess each individual case and decide if the persons' organs and tissues are suitable for donation.

Organ donation takes place within established time frames that can differ depending on the type of organ donation, the availability of specialist teams and donation environment, and the clinical stability of the donor. These time frames will be fully explained by a Specialist in Organ Donation.

Further information can be sought by accessing the NHS Blood and Transplant Organ Donation webpage - [Home - NHS Organ Donation](#)

What is Tissue Donation?

Tissue Donation is the donation of tissues such as eyes, skin, heart valves, bones, tendons, meniscus and femoral arteries to be used in life transforming transplant procedures. Tissue donation takes places after a person has died, however unlike organ donation a person does not need to die in specific circumstances to be considered for tissue donation. Specialist Nurses for Tissue Donation will assess referrals for potential suitability for donation and will support the family through the assessment and consent process.

Most Tissue Donation must take place within 48 hours of death, though for certain tissue types, such as eyes, donation needs to take place within 24 hours of death.

Further information can be sought by accessing NHS Blood and Transplant Tissue Donation webpage - Tissue and eye services - NHS Blood and Transplant

Can children donate?

Anyone can register a decision to become an organ or tissue donor. Children and Young People under the age of 12 in Scotland and under 18 in the rest of the UK at the time of registration will require their parent or guardian's agreement for donation to take place. Parents and guardians can register the children, and children can register themselves.

Having an illness or medical condition does not necessarily prevent a person from becoming an organ or tissue donor. In all cases, the decision about which organs and tissues are suitable for donation is made by specialist healthcare staff, taking into account medical, travel and social history. There are very few conditions where organ donation is ruled out completely e.g. active cancer. This means there is a possibility for children with a life-threatening or life-limiting condition and their families to consider organ or tissue donation. Many children are able to donate tissue even when their diagnosis or situation excludes them from donating their organs. Specialist healthcare professionals will help decide in each individual case whether a person's organs and tissue are suitable for donation.

Organ donation can be considered at all ages. For tissue donation, there are certain age limitations or additional requirements that may need to be considered as listed below:

- **Eye Donation** - Whilst there is no absolute age contraindication, any potential donor under the age of 3 years may require further assessment and discussion with the National Referral Centre and, where applicable, the mother of the child may be requested to undertake further testing (if the child is under the age of 18 months or has been breast fed in the preceding 12 months to death).
- **Heart Donation** - There is a minimum age requirement of 32 weeks gestation, though as with Eye Donation there may be a requirement for further assessment and testing.

- **Skin Donation** - There is no minimum or maximum age requirement for skin donation, though additional assessment and testing may be required as with Heart and Eye donation.
- **Bone & Tendon Donation** - has a minimum age requirement of 17 years to be eligible for donation.
- **Costal Cartilage** - has a minimum age requirement of 10 years to be eligible for donation

What does the legislation say?

Organ and Tissue Donation is governed by the Human Tissue Act (2004) and governed by the Human Tissue Authority. The Human Tissue Act encompasses all aspects of removal, storage, and use of human tissue, focussing on four key principles: Primacy of consent, Dignity, Quality and Honesty & openness.

The Organ Donation (Deemed Consent) Act 2019 establishes an “opt-out” system for organ and tissue donation, presuming consent unless individuals explicitly decline donation. Whilst the Act excludes people under the age of 18, the general principles regarding establishing wishes, supporting people to share those wishes and advocating for their right to choose are applicable across all person-centred care processes.

Advance Care Planning for Organ and Tissue Donation

The earlier that a wish can be established, the longer staff have to support the person and those important to them to understand the donation process and the requirement for assessment and consent to be put in place, as well as providing those caring for the person with the information needed to make a referral at the appropriate time.

There is a section within the advance care plan to prompt conversations about organ donation, and this enables parents to talk in advance and to seek further information. Research shows that parents value being informed about organ donation and appreciate the opportunity to discuss it (Bennett 2023).

Whenever possible, these conversations are best held before a child dies. The earlier a conversation can be facilitated, the more likely it is that donation can be supported. Such conversations require sensitivity and clear communication, so families have time to understand the options given their child's condition and to be fully informed regarding preferred place of care and immediate care after death.

It is important to note that if a family chooses organ or tissue donation this may influence place of death, as organs and tissues must be retrieved within specific timeframes to remain viable, and cooling the body in specific cooling facilities (rather than a blanket or a cot) within 4 hours is optimal (NEOLCP 2014).

In all cases where organ or tissue donation is pursued, there must be a defined cause of death and all processes must adhere to the Human Tissue Act (England, 2004/22 and Scotland 2019/23). Because these requirements influence place of care and place of death, professionals must ensure families are aware and fully informed and their wishes clearly documented in the Advance Care Plan (ACP). Professionals should know who to contact in the event of death, to facilitate verification, ensure timely retrieval and support families wishes.

Additional information

For further information or to talk to someone about Organ Donation go to:

- Organ Donation website: [Home - NHS Organ Donation](#)
- National Phone number: 0300 123 23 23

For further information or to talk to someone about Tissue Donation go to:

- Tissue Donation website: [Tissue and eye services - NHS Blood and Transplant](#)
- National Phone number: 0800 432 0559

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