

UNBORN BABY WITH SERIOUS ABNORMALITIES

ORGAN DONATION OPTIONS – INFORMATION LEAFLET



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Introduction

We are very sorry indeed to hear that your unborn baby has been found to have such a serious problem that, despite the best medical care, your baby is unlikely to survive.

You have been given this leaflet to allow you to consider options for organ and tissue donation.

Whatever you decide is entirely up to you and you can change your mind at any time, even right up to the last minute. You will be supported by the team looking after you at all times, whatever decision you make.

Which organs and tissue can be used?

These organs and tissue can potentially be used to save or transform the lives of people waiting for a transplant:

- Kidneys
- Liver cells
- Heart valves
- Lungs (in limited circumstances).

In some cases, tissue such as liver cells can be used to keep a baby or young child alive; a baby's kidneys will often be given to a young adult and heart valves are most often used to repair congenital heart abnormalities.

Practicalities

For your baby to be a donor, a number of things need to come together:

- Your baby would need to be born after 36 weeks of pregnancy
- Your baby would need to be born alive
- The implications for how, when and where your baby would be born would need to be discussed with you.

Despite this list of challenges, successful organ and tissue donation from babies with severe abnormalities has occurred in the UK and has made a huge difference to the lives of those who have received those organs or tissue.

Organ and Tissue Donation

Organ and tissue donation saves lives. While losing a baby is always extremely upsetting and emotionally painful, parents whose child or baby has donated usually find, in the longer term, that this can give some comfort.

“In pursuing organ donation, we hoped we may bring life and joy to another family” - J.M., mother.

“It helped us grieve. Knowing that he was able to do such good, more good than most of us will ever do in our lifetime – it is just overwhelming how proud we are of him.” – parents of baby Teddy, the UK’s first newborn baby organ donor.

In your baby’s case, we would be able to consider donation when the heart stops beating and breathing stops. This is known as circulatory death. For any organs to be donated, the baby has to be taken to an operating theatre as soon as possible after death for the donor operation.

What next?

If you would like to find out more about these possibilities, then you can meet a Specialist Nurse in Organ Donation and talk through all the issues in more detail. Usually this meeting will be in conjunction with your local team of doctors and midwives. Please speak to your doctor and they will arrange this for you. We suggest you make a note of any questions you may have in advance.

Other information

Organ Donation Scotland website –
see <https://www.organdonationscotland.org/>

We recommend that you visit the 'Tell me more' section in particular.