

# Kidney transplant – deceased donors



infoKID

Information for parents and carers about children's kidney conditions

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Each topic starts with an overview followed by several sections with more information.

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A kidney transplant is an important treatment for children with established renal failure (ERF) – when the kidneys are in failure and cannot get better. This is the final stage of chronic kidney disease (CKD). A kidney transplant is currently the best treatment for almost all children with ERF.

A healthy kidney is removed from one person (a donor) and placed in the body of another person who needs it (a recipient). Transplanted kidneys come either from a living person donating one of their kidneys, or from people who have recently died.

This second type of donor is called a deceased donor and this topic deals with the particular issues relating to deceased donor transplants.

→ We recommend you read [Kidney transplants – an introduction](#) first. For further information about living donor kidney transplants, read [Kidney transplant – living donor](#).



## Overview

If your child needs a kidney transplant, he or she can be added to the **national transplant list**, which is also called the waiting list. Your child will then wait for a suitable kidney from a **deceased donor**, someone who has recently died. Although children are prioritised on the waiting list, it can take up to one year and sometimes longer before a suitable donor is found and the kidney transplant takes place.

This topic gives you information about deceased donor transplants. This topic covers:

- what information you may be told about the donor
- how kidneys are allocated (given) to children on the national waiting list
- about being on the waiting list while waiting for a possible kidney transplant from a living donor
- what happens when a kidney becomes available for your child
- specific risks associated with receiving a deceased donor kidney transplant.

→ We recognise that this may be a time of a lot of uncertainty and stress. Your child's transplant team, a group of healthcare professionals who specialise in children's kidney care and transplantations, will support your child and family throughout the entire process.

### About this information

These topics are to help you understand the whole process of receiving a deceased donor kidney transplant well before the time it happens. You will have time to think about the details and risks of the operation, and lots of opportunities to discuss it with your child's transplant team.

This information covers children and young people aged under 18 who are treated in a **paediatric renal unit** – a special unit for babies, children and young people with kidney problems.

### Acknowledgements

This leaflet has been co-authored with Martin Christian, Consultant Paediatric Nephrologist, Nottingham Children's

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## Preparing for a kidney transplant from the transplant list

While doctors usually try to share information as openly as possible, kidney transplantation is an unusual situation in which two people are involved – a **donor** (the individual giving the kidney) and a **recipient** (the individual receiving the kidney – your child). It may not be possible to tell you much about the donor because it is important to respect the privacy of the donor and his or her family.

Your child's **transplant surgeon** (the surgeon who manages the operation) and **paediatric nephrologist** (doctor who treats babies, children and young people with kidney problems) will usually make the decision about the most suitable donor for your child's kidney transplant.

The different types of kidney transplant have different risks. You will be able to speak with your child's transplant team about the type of transplant you are not willing to accept. Some requests may change the amount of time your child will need to wait before a transplant.

## Consent

As a parent or main carer of your child, you will need to give **consent** (agreement) before he or she goes on the transplant list. You will be asked to read and sign a form that confirms you understand all of the complications and risks, and agree to your child going on the transplant list. You may also be able to sign a consent form for the kidney transplant itself. However, you will need to confirm your consent when your child is admitted to the hospital for the operation.

If your child is an older child or a young person, he or she will be encouraged to learn more about the transplant and provide consent for himself or herself.

This consent is not simply about your signature on a piece of paper. Rather, it is a process of understanding more about the operation and what is best for your child. This topic, together with the two topics on **Kidney transplants – an introduction** and **Kidney transplants – living donors**, can help you in this process.

# About deceased donors

**A deceased donor is a person who has recently died, has given permission for his or her organs to be used for transplantation, and whose body organs, such as the kidneys, are considered to be in a healthy condition and suitable for transplant. This type of transplant is known as a deceased donor transplant or a cadaveric transplant.**

## National transplant list

If your child needs a kidney transplant, he or she can be added to the national transplant list, which is also called the waiting list. Your child will then wait for a suitable deceased donor for his or her new kidney. Although children are prioritised on the national transplant list, it can take up to one year and sometimes longer before a suitable donor is found and the kidney transplant takes place.

## Matchability score

There is more basic information about matching in the general transplant leaflet and it would be helpful to read this first. When your child goes onto the transplant list he/she will be given a **matchability score**. This score tells the transplant team how easy or difficult the patient is to match, based on the blood group, tissue type, and any antibodies made against mismatched antigens from previous transplants or blood transfusions.

The scores are ranked from 1 (easy to match) to 10 (difficult to match). If your child has a score of:

- 1, 2, 3 or 4 – he or she is likely to be matched with a donor and have a kidney transplant within a year
- 5 or 6 – he or she may have a kidney transplant within a year, but may take longer
- 7, 8, 9 or 10 – there is a strong possibility he or she will wait longer than a year to have a kidney transplant

Your doctor will be able to discuss your child's matchability score with you once he or she is accepted on the waiting list. This may help you to consider options for living donation.

## When a less well-matched transplant happens

### » Read more about matching levels in **Kidney transplant – an introduction**

If a child is on the transplant list for more than one year (while they are on dialysis), your transplant team may decide to accept a less well-matched transplant. This increases the chance of your child getting a transplant. Your nephrologist (kidney specialist) will usually make the final decision. If you have any concerns, or if you feel you would rather wait longer for a more acceptable match, you should discuss this with your doctor.

Donors stay **anonymous**, which means that the family and child receiving the donation do not know who the donor is. Some families wish to express thanks to the relatives of the donor, and this can be done in a letter sent through the transplant coordinator or nurse.

→ **Once a potential donor is identified, your child needs to be ready to go into hospital straight away for tests. If your child is well enough and if the kidney is confirmed to be suitable, the transplant surgery will be done as soon as possible.**

## When someone becomes a donor

Adults in the UK may register on the **NHS Organ Donation Register**. A growing number of people are on the Register – they agree to give one or more of their organs, such as their kidneys, in the event of their death. This gift helps one or more people who need a transplant.

If doctors think that a patient on a life support machine is unlikely to recover (get better and survive), they will test his or her vital functions, such as breathing. If these tests show that the patient's vital functions are completely damaged because of brain damage, they will advise that treatment should be stopped because there is no chance of the person recovering.

The doctors will then speak with the patient's family to consent to switching off the life support machine. A **specialist nurse in organ donation (SNOD)** is a specially trained nurse who supports families during a donation. A SNOD may meet with the family to discuss the possibility of using their loved one's organs to help one or more people who need them. Some patients will have previously registered on the Organ Donation Register, which shows that this is what they would have wanted and makes this process easier.

As soon as the family gives consent for organ donation, healthcare professionals will test the deceased patient as a possible organ donor. If his or her organs are healthy, these are removed and then quickly and safely transported to the transplant centres where they are needed.

## Types of deceased donors

There are two types of deceased donors in kidney transplantation:

- donors after brain death (DBD)
- donors after circulatory death (DCD).

### Donors after brain death (DBD)

A **donor after brain death (DBD)** is someone who has died of an illness or injury from which the brain cannot recover. The person's other organs, including the kidneys, are usually in a healthy condition. Once the donor's family consents, the donor's organs are removed while the heart is still beating and pumping blood around the body.

There is always a period of time between removing a kidney from a donor and placing it into the recipient. This is called the **cold ischaemia time**. Transplant surgeons try to keep this as short as possible, but within 18 hours, with DBD transplants.

### Donors after circulatory death (DCD)

A **donor after circulatory death (DCD)** is someone who has died because his or her heart has stopped working.

Once the donor's family consents, the donor's organs are removed after the heart has stopped beating. Because the donor's heart is not pumping blood, the kidneys and other organs do not have blood flow for a short period of time after death and before they are removed.

There is always a period of time between removing a kidney from a donor and placing it into the recipient. Transplant surgeons try to keep this time as short as possible with DCD transplants because the kidney will have not had blood flow for a short period of time before they are removed.

Until recent years, kidney transplants were always from DBDs. The number of people waiting for organ transplants is increasing every year. In recent years, transplant surgeons have started using kidneys from patients who have died because their hearts stopped working. Most DCD kidney transplants have been used for adult recipients, but some have been used in children.

## Particular risks for DCDs

The experience so far in DCD kidney transplantation is that the kidneys may take longer – up to several days – to start working. This is called **delayed graft function**.

Once the DCD transplanted kidneys do start working, they seem to do as well as DBD transplanted kidneys. One year after the operation, there seems to be no difference in how many kidneys are still working between DBD and DCD kidney transplants.

» [More information about matchability](#)

## Your options

For more information about the additional risks, speak with your transplant team. You may decide that you do not want your child to have a DCD transplant, but you should discuss this first as it may increase the amount of time your child waits for a transplant.

## Information about a deceased donor

### Medical history

Before donors' organs are removed for transplantation, they have a complete medical history check and are tested for serious infections such as HIV and hepatitis (liver disease).

It is not possible to share all of the donor's medical information with you, to respect the donor's privacy.

» [List of medical information about the donor that is collected](#)

### Which medical problems are not accepted

Deceased donors with a history of medical problems such as cancer, HIV or other infectious diseases will not usually be considered for donation to children. Those with a history of other problems such as diabetes or severe hypertension (high blood pressure) are also less likely to be considered for children unless there are other good reasons for going ahead with the transplant.

» [List of medical conditions that makes a donor unsuitable for children](#)

## Age

Most deceased donors for child recipients are aged between 5–50 years.

Deceased donors are occasionally children. However, kidneys from children aged less than 5 years are usually not accepted. This is because there is a higher risk of the transplanted kidney not working because of **thrombosis** (when the blood vessels are blocked with a blood clot).

Occasionally, kidneys from smaller children and infants are transplanted as a pair ('en-bloc') into the recipient. Your child/s transplant medical team may discuss this with you.

## Anonymity and saying thank you

When specialist nurses for organ donation talk to relatives about donating their loved one's organs, it is on the understanding that the donor stays anonymous (which means that the family and child receiving the donation do not know who the donor is).

Transplant staff understand that recipients or their parents may feel they want to express their thanks to the relatives of the donor and this can be done in an anonymous way after the transplant, by writing a letter. The transplant nurse or coordinator will be able to tell you more about this.

# Transplant list

Children and adults who need transplants are added to the national transplant list, which is also called the waiting list.

## Being on the transplant list

Many people wrongly think that the transplant list is like a waiting list for other types of operations – you start at the bottom and slowly work your way to the top. It is better to think of the transplant list as a lottery, which means your child can get a kidney after a very short wait or after a long wait.

The average wait for a deceased donor kidney transplant for a child is around one year. This will vary depending on your child's **matchability score**. This is available once your child goes onto the waiting list and your child's consultant should discuss it with you then.

## When a child is put on the transplant list

Your child's nephrologist (kidney specialist) will decide when your child is ready for a kidney transplant.

- Often, children may have a kidney transplant before they need dialysis. This is called a pre-emptive transplant.
- Other children may need to have dialysis first for a number of reasons:
  - if the kidney failure only presents itself just before your child needs dialysis, there will not be time for the medical preparation for a pre-emptive transplant
  - even for children who have had kidney failure for some time, there are some medical reasons why they need to have dialysis before a transplant.

## Being on the transplant list while a living donor is having tests

If you or someone else would like to be a living donor and give one kidney to your child, there will be a series of tests over some time. These will find out if there are any risks to the living donor and if there is a close match to your child. While this is happening, your child may continue to be on the transplant list for a deceased donor.

If early results of the living donor work-up are encouraging, you may wish to review your child continuing to be on the waiting list. If you do decide that your child should remain on the waiting list, your child's doctor may suggest further restrictions on the waiting list matching at this point, based on the living donor's tissue type. This will help make sure that the living donor could still donate a kidney to your child in the future if they needed another transplant. If a decision is made to proceed with living donation, your child will usually be taken off the national list once a date for living donation has been set. You can discuss all of these issues with your child's doctor in more detail.

## Read more about why a deceased donor and a living donor can't share antigens

If someone receives a donor kidney that is mismatched, his or her body will recognise it as foreign tissue and will destroy it.

If your child receives a kidney from a deceased donor that shares antigens with a future living donor (for example, a parent), your child **can no longer** receive a kidney from that living donor in the future. This is because your child will be **sensitised** to the antigens from the deceased donor, and therefore reject a kidney with this antigen in the future.

» [Read more about matching and HLAs in Kidney transplants – an introduction](#)

» [Read more in Kidney transplant – living donor](#)

## When a kidney becomes available

When a kidney becomes available, a central transplant office will contact your local **transplant coordinator**, someone who manages organ transplantations, to make the offer. This will then be discussed with the transplant surgeon (the surgeon who manages the operation) and the consultant paediatric nephrologist (doctor who treats babies, children and young people with kidney problems) on duty. They will consider all of the known medical information about the donor, and decide whether this is a suitable donor for your child. If you have made special requests about the type of donor, these will be considered.

Most kidney offers are made as soon as the donor's HLA type is known (see **Kidney transplants – an introduction**) – this is usually before the kidney has been removed. The transplant coordinator, or another person from your paediatric renal unit (special unit for children with kidney problems), will contact you. This may be after the kidney is removed from the donor and your doctors confirm the match. Or, if you live far away from the unit, this may be as soon as the kidney offer is made.

## Crossmatch at the hospital

When your child arrives at the hospital, he or she will have several more blood tests. These include an **immunological crossmatch**, which tests for any reaction between a sample of your child's blood and a sample of the donor's blood. The result can take up to four hours. If there is no reaction – if the result is 'negative' – the transplantation can take place.

If this is your child's first transplant and he or she has no or stable levels of antibodies on regular blood tests, and has not had a blood transfusion in the last 12 months, then it is extremely unlikely that the crossmatch would be positive and prevent the transplant taking place. The actual crossmatch is still done but the operation does not need to wait for the result. This is called a **virtual crossmatch**. This is sometimes done to reduce the cold ischaemia time – time from removal to transplant – and is particularly important for DCD transplants where a short cold ischaemia time reduces the risk of **delayed graft function**. Your child's doctors will look at his or her earlier blood test results for any **antibodies** that might attack the transplanted kidney.

## Additional information

### Donor data collected

Specialist nurses for organ donation collect detailed information about the donor's medical history from hospital medical records and from relatives. This is in order to ensure that it is as safe as possible for the kidney to be donated. This includes information about

- their general health, including particular health conditions and treatments
- behaviour that might affect their health, such as drinking alcohol, taking drugs and sexual history
- a history of recent travel to other countries, where the donor might have been at higher risk of infectious disease.

Please remember this information cannot be shared with you. It helps your transplant team make a decision about which donors are suitable for your child's transplant.

### Reasons to decline kidneys for recipients who are children

There are some situations in which donors are *not* or are *rarely* used for kidney transplants in children. Your transplant team will use this information to decide whether a potential donor kidney is suitable for your child's transplant.

### Reasons why a kidney will not be used

If a donor has a known life-threatening disease that may be transmitted in the donated kidney, their organs, including kidneys, will *not* be used for a transplant in a child. Examples of these types of conditions are HIV disease and cancer that has spread. These conditions are listed in the more information box.

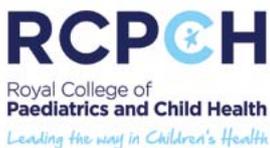
## Read more about when a kidney will not be used because a donor has a condition

Donors with the following life-threatening conditions will not be used for a transplant in a child:

- HIV disease
- Cancer that has spread
- Diseases like Creutzfeld–Jakob disease (CJD – the human form of mad cow disease)
- Active tuberculosis (TB)
- Swine flu, unless the donor has been well treated with antiviral drugs first

# Your notes and contact information

[www.infoKID.org.uk](http://www.infoKID.org.uk)



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For details on any sources of information used in this topic, please contact us through our website [www.infoKID.org.uk](http://www.infoKID.org.uk).

We take great care to make sure that the information in this leaflet is correct and up-to-date. However, it is important that you ask the advice of your child's doctor or nurse if you are not sure about something. This information is intended for use in the United Kingdom, and may not apply to other countries.

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