

Kidney transplant – an introduction (Overview)

This infoKID topic is for parents and carers about children's kidney conditions.

This leaflet has the overview only.

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

Kidney transplantation is major surgery. A healthy kidney is removed from one person (a donor) and placed in the body of another person who needs it (a recipient). Children need to have many tests before the operation, and may need to wait for up to a year or longer before a suitable kidney becomes available. The operation takes a few hours, and children usually need to stay in hospital for ten days or longer to recover and to check that the new kidney works well. Children will always need to take medicines, go to follow-up appointments and take care of their health for years after the transplant.

A kidney transplant is currently the best treatment for almost all children with ERF. After a successful transplant, children can live healthy lives and feel much better. A new kidney may work for many years. Children may need further kidney transplants, dialysis or other care later in life.



→ We recognise that this may be a time of a lot of uncertainty and stress. It is important that your child is prepared for both the operation and the after care. 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

This information aims to help you understand the process of kidney transplant for your child 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. It covers:

- why your child may benefit from a kidney transplant, and when it is needed
- types of kidney transplant – including live donor and deceased donor (also covered in separate topics, see [Kidney transplant – deceased donor](#) and [Kidney transplant – living donor](#))
- complications and risks, including 'kidney rejection', and alternatives to transplantation

- your child's kidney transplant team
- what happens before the transplant, including tests and 'matching', and how to prepare your child
- what happens during the transplant surgery
- what happens after the transplant surgery, and what to do when you get home.

Acknowledgements

This leaflet has been co-authored with Martin Christian, Consultant Paediatric Nephrologist, Nottingham Children's Hospital and Dr Stephen Marks, Chair of NHS Blood and Transplant paediatric kidney advisory subgroup.

About the urinary system

The **urinary system** gets rid of things that the body no longer needs, so that we can grow and stay healthy.

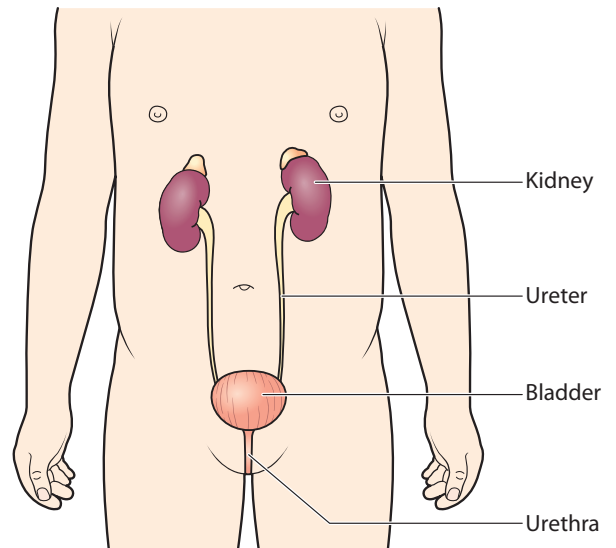
The **kidneys** are bean-shaped organs. They filter blood to remove extra water and waste in urine (wee). Most of us have two kidneys. They are on either side of our spine (backbone), near the bottom edge of our ribs at the back.

The two **ureters** are long tubes that carry urine from the kidneys to the bladder.

The **bladder** is a bag that stores urine until we are ready to urinate. It sits low down in the tummy area.

The urethra is a tube that carries urine from the bladder to the **outside** of the body.

» [More about the urinary system and kidneys](#)



About kidney transplant

Any human tissue – including a kidney – that is transplanted from one person to another person is also called an **allograft**, or **graft**. If transplantation is successful, the graft can survive for many years. Your child may need one or more transplants and/or dialysis later in life.

Why does my child need a kidney transplant?

A kidney transplant is offered to children in the final stage of **chronic kidney disease (CKD)**. CKD is a lifelong condition in which the kidneys stop working as well as they should. This happens slowly, over many years. There are five stages in CKD. In stage 5, the kidneys can no longer support the body and are in failure. This stage is known as **established renal failure (ERF)** or **end-stage renal failure (ESRF)**.

» [Read more in the infoKID topic Chronic kidney disease – stages 3b-5](#)

In ERF, many children need **dialysis**, a treatment that cleans the blood because the kidneys are no longer able to do so. However, dialysis does not do *everything* that kidneys do – such as help keep bones healthy and ensure red blood cells are made. Children may continue to have symptoms and often need to restrict what they eat and how much they drink.

Benefits

A kidney transplant does not cure kidney failure. However, a successfully transplanted kidney means that children can stop dialysis, feel better, and start to eat a normal, healthy diet so they can grow and develop. With careful after care, including regularly taking medicines, the new kidney can work for many years. Children will need to visit the hospital regularly in the months after the operation. Over time, these appointments will usually be less frequent.

Who can have a kidney transplant?

Almost all children with ERF can have a kidney transplant. Your child will have many tests to make sure he or she is ready and able to have this operation.

Babies and younger children under 2 years may need to wait until they grow to a size that allows a transplant to take place.

When it happens

Because your child needs to wait for a suitable kidney to become available, he or she may need to wait up to a year or even longer.

Sometimes, a kidney transplant can take place *before* a child needs dialysis and while the kidneys are still able to support the body. This is called a **pre-emptive transplant**. A pre-emptive transplant is not always possible. The timing of a transplant depends on many factors. Many children need dialysis while they wait for a kidney that is right for them.

Types of kidney transplants

There are two types of donors for a kidney transplant.

Deceased donor

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**.

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 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.

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 – this may be at any time of day or night. 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.**

» **Read more in the infoKID topic: Kidney transplant - deceased donor**

Living donors

A **living donor** is a living person (an adult) who agrees to give one of his or her two healthy kidneys to a recipient. This type of transplant is known as a **living donor transplant**. These transplants are often more successful than deceased donor transplants. This is because the kidney is transplanted soon after it has been removed so that the time a kidney is without blood and oxygen is kept to a minimum.

Living donors are usually related to the child. This is often someone who is biologically related to the recipient – this increases the chances that the donor's kidney will be suitable. These living donors are known as **living related donors**.

→ **The transplant surgery from a living donor is almost always planned well in advance. A kidney will be removed from the living donor, and then transplanted into your child as soon as possible and on the same day. The living donor may be in a different hospital, which treats adults.**

Some people choose to donate a kidney without a particular recipient in mind. They are known as **altruistic donors** and, though still fairly uncommon, the number of altruistic donors has increased in recent years. These donations are made available through the national transplant list, described above. They are anonymous, though you may be able to find out the sex and approximate age of the donor, and you will have a chance to write a letter to express thanks if you wish.

Sometimes, when a donor and recipient do not have a match, it is possible to swap a donor kidney with another donor and recipient pair in the same situation. This is called a **paired exchange**, where each recipient receives a kidney from a donor they do not know. When more than two pairs are involved, it is called a **pooled exchange**.

Paired and pooled exchange is part of **NHSBT's National Living Donor Kidney Sharing Scheme**.

Benefits of living donor kidney transplantations

The results with kidney transplantations from living donors are better than those with deceased donors. From 1997 to 2001, the percentage of kidney transplants in UK children that were working ten years after the transplantation was:

- deceased donor transplants – 64%
- living donor transplants – 71%.

If there is a suitable donor available, your child's **paediatric nephrologist** (doctor who treats babies, children and young people with kidney conditions) may encourage you to choose a living donor transplant only.

Being a living donor

Potential living donors will have many tests to make sure they are prepared for the operation to remove a kidney and that they will be able to remain healthy with one kidney. They usually need to stay in hospital for 2-4 days or longer depending on their recovery, and then have time off work to rest, for between 6 weeks and 3 months. Donors may be paid for expenses and loss of earnings.

If you are considering being a living donor, speak with your child's transplant team. This is an important decision, and you will have many things to consider. The following resources may also help:

- **Could I be a living donor? (NHS Blood and Transplant)**
- **Donating a kidney: What to expect (British Kidney Patient Association)**

» **Read more in infoKID topic on Kidney transplant - living donors**

Risks and complications

Kidney transplantation is a big operation with a lot of possible side-effects and risks to consider. Your child's transplant team will carefully monitor your child and check for signs of complications during and after the operation. They will discuss these with you in detail.

You will need to give written agreement (**consent**) before transplantation.

The most important risks include the following.

- **Complications** during or immediately after the operation – these include losing a large amount of blood, difficulties breathing because of too much fluid in the body, infection, and seizures (fits). Other problems during the surgery may result in too little blood going into your child's new kidney, or a blockage that affects how your child's kidney drains urine. Sometimes the **ureter** (the tube between the kidney and bladder) is damaged and urine may leak. Your child's transplant team will minimise these risks and monitor for any warning signs, so problems can be treated as soon as possible. Occasionally, follow-up surgery is needed.

- **Delayed graft function** – your child’s new kidney may take some time – up to several weeks or occasionally longer – before it starts working, especially if it is from a deceased donor. Occasionally, children need dialysis for some time before the kidney is fully functioning.
- **Rejection** – the body’s immune system may ‘reject’ the new kidney. This may happen suddenly (**acute rejection**) or over a longer time (**chronic rejection**). Your child’s transplant team will find the most suitable kidney available for your child and your child will take anti-rejection medicines to reduce this risk.
- **Thrombosis (blood clot)** – occasionally, if a blood clot is large, it can block the blood flow to the kidney.
- **Graft loss** – occasionally, the new kidney does not work for one of the above reasons or another reason.
- **Problems due to medicines** – all transplant patients need to take anti-rejection medicines (called **immunosuppressants**) throughout the life of the new kidney. These help reduce the risk of rejection, but mean that children are at greater risk of **infections** and of getting more ill than usual. Some anti-rejection treatments can upset the kidney function when taken for a long time, so the level of drug in your child’s body needs to be checked. This is to make sure that your child’s kidney function remains as good as possible by avoiding rejection while also avoiding blood levels of drug that are harmful to the transplant.

Alternatives

The alternative treatment to a kidney transplant is continued dialysis. Dialysis is an important, life-saving treatment, and if a transplant is not done will need to be continued. This option is not recommended for most children. You will need to discuss the effects of long-term dialysis with your child’s healthcare team.

» Read more in the infoKID topic Dialysis – an introduction

If children do not have a kidney transplant or dialysis, their kidneys will eventually stop working, so that they can no longer support the body and they will die. This is called **conservative treatment** or **palliative treatment**. Children are made as comfortable as possible – but may continue taking medicines and restricting their diet and fluid intake to manage symptoms and control pain.

A very small number of children with kidney failure may not benefit from dialysis or a transplant – usually because they have other complicated health problems. Your child’s healthcare team will support you and your family throughout this time.

Matching

When a kidney – or any other body tissue – is transplanted from a donor to a recipient, the recipient’s body recognises it as ‘foreign’ and tries to reject or destroy it. This happens because of the **immune system**, which protects the body against disease and infection. This is called rejection, and is the major complication of kidney transplantation.

There are two ways to reduce the risk of the new kidney being rejected:

- ensuring a ‘close match’ between your child and a donor
- taking medicines from the day of the transplant for the entire life of the new kidney.

Ensuring a close match

Blood tests before and on the day of the transplant check for ‘markers’ on the body’s cells. These markers are inherited from our mother and father. These tests help to find a donor who is a close ‘match’ to your child – which increases the chance of a successful transplant. There are two important types of tests.

- **Blood group:** our **red blood cells**, one type of living cell in the body, belong to a blood group. These are: A, B, AB and O. It is important that your child’s blood group is compatible (can match) with the donor’s blood group.
- **Tissue typing for HLAs:** our ‘tissue-type’ is based on proteins called **human leukocyte antigens (HLAs)**. These are determined by our **genes**, which are passed down by our mother and father. HLAs are on most cells in our body, and are part of the immune system. There are many possible combinations of HLAs, so it is difficult to find a perfect match. However, your child’s transplant team will check the tissue-type of your child with that of a potential donor, for a match that is close enough.

Medicines

Immediately before the surgery, and after the transplant, your child will need to take medicines that **suppress** his or her immune system, or make it less active – these medicines are called **immunosuppressants**. They aim to stop your child’s immune system from rejecting the transplanted kidney. Your doctor will work out a personal medicines plan that is right for your child.

→ It is very important that you follow your doctor’s instructions about what and how much to give.

Preparing for a kidney transplant

Where you will be seen

Most UK **paediatric nephrology units** do kidney transplantations in children. A few do not, but instead work with another unit to coordinate the surgery. You will probably continue going to your regular unit for tests. However, you may need to travel to another unit – which may be further away from your home – for the surgery, and for meetings with the transplant team.

Transplant team

You will meet the **transplant nurse** (or **transplant coordinator**), who will give information and support before, during and after transplantation, and organise the timing of your child's surgery. You will also meet the **transplant surgeon**, who will lead the team that carries out your child's surgery. Your child's **paediatric nephrologist** will continue to manage your child.

Tests before the transplantation

Your child will need many tests to make sure he or she is ready for a transplant. These include a series of **blood tests**, as well as some **imaging tests** (scans), especially to check that his or her heart and blood vessels are healthy. Sometimes other tests are needed. These tests often start during stage 4 CKD when your child is preparing for treatment for stage 5 CKD.

Your child will need to continue going back to the unit for further tests while he or she waits for the transplant – often up to a year or longer.

Consent

As a parent or main carer of your child, you will need to give **consent** (agreement) before he or she has a living donor transplant or goes on the deceased donor 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 having a transplant. 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 **deceased donors** and **living donors**, can help you in this process.

Coming to the hospital

You will be told when you need to come to the hospital – this depends on whether your child will have a living donor or deceased donor transplant. As your child will be at the hospital for some time, you should bring clothes, toiletries, toys and books. You can speak with the transplant team about any arrangements for you and your family staying at or near the hospital.

Some tests need to be done on the day of the transplant itself. Your unit may not be able to go ahead with the operation if your child is ill – for example, with a cold or fever. Children need to start taking immunosuppressant medicines just before the operation, and because these make the immune system less active, your child would be less able to fight the illness.

→ It is important that your child goes to the unit for all tests.

About the surgery

The surgery takes a few hours, and is done by a **transplant surgeon**, who specialises in transplantations. It is done at a **paediatric renal unit** – this is a special unit for children with kidney problems and may be the same unit where your child has been treated before, or another one that does kidney transplantations.

Your child will be moved into an **operating theatre**. The transplant surgeon and team will make sure your child is as comfortable as possible. They will use **general anaesthesia** so your child is asleep through the surgery and cannot feel pain. Your child will be given antibiotics to prevent infection. He or she will also have other pain medicines to control pain immediately following the operation.

The kidney that is to be transplanted also has the ureter and two main blood vessels that carry blood in and out of the kidney, the **renal artery** and **renal vein**, attached.

When your child is asleep, the surgeon will make a cut into his or her abdomen (tummy). The new kidney will be placed low down in your child's abdomen to one side. The kidney's blood vessels will be joined up with your child's large blood vessels, so that blood can flow in and out. The new ureter will be joined to your child's bladder, so that urine can flow from his or her kidney into the bladder.

Your child's own kidneys will probably be left in place. One or both are only removed if they are causing problems.

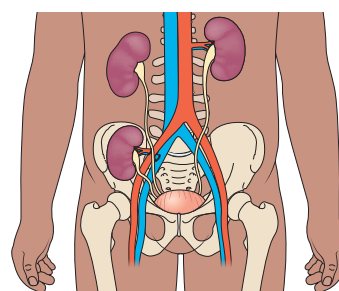


Illustration of where a transplanted kidney sits

After the operation

Your child will be taken back to the ward of the paediatric renal unit to recover from the operation. Sometimes, children need to be taken to the **paediatric intensive care** unit – especially if they are very young or small, or if there are any complications during the surgery.

You will be told when you can visit your child. He or she will have lots of tubes in place that were put there during surgery. These help monitor your child's blood pressure and how much fluid (liquid) is in his or her body, allow medicines to be given and blood to be taken, support breathing, and collect urine using a **urinary catheter** – a thin, flexible tube – that drains urine from the bladder. The **transplant surgeon** will decide when the catheter should be removed, this is usually 4–7 days after the operation.

Some children need a **wound drain**, which collects any extra fluid from the surgery – this is removed after several days.

Your child will be given medicines to relieve pain after the surgery. If he or she is old enough, your child may be allowed to control how much pain medicine he or she gets – this can be usually done by pressing a button that gives the medicine through a **cannula** (a plastic tube inserted into a blood vessel in his or her arm). Your child will not be able to give too much medicine. Your doctor or nurse will give you more information.

Supporting your child

This can be a difficult and stressful experience for your child and the whole family, including other children. You and your child will learn more over time about kidney transplants, and how to help manage and live with CKD.

Your child's healthcare team is there to help you. They can provide support with your child's education, accessing financial benefits, and planning holidays around tests and treatments.

Other families

Speaking with other families of children who have undergone a kidney transplantation, can also be a huge support. Speak with your healthcare team for more information.

→ If you have any concerns or need additional support, speak with your doctor or nurse.

» More about kidney transplant on www.infoKID.org.uk

Your notes and contact information

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.

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