

Kidney transplant – an introduction



infoKID
Information for parents and carers about children's kidney conditions

This infoKID topic is for parents and carers about children's kidney conditions. Visit www.infoKID.org.uk to find more topics about conditions, tests & diagnosis, treatments and supporting information.

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

» [Links to sections](#) in topic | [Other topics](#) available on website

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.

Overview

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.

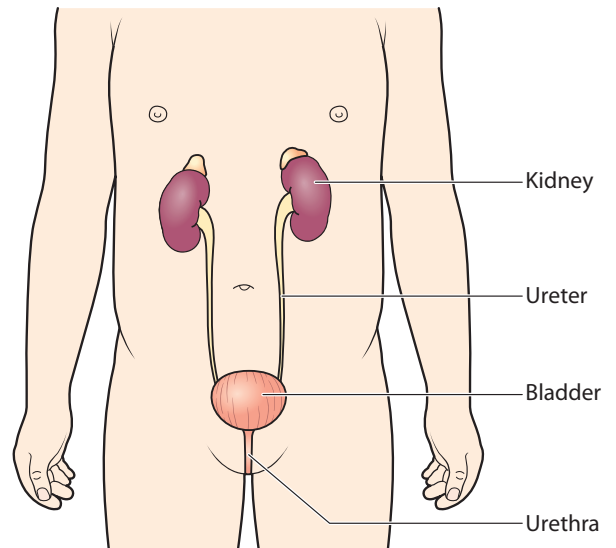
The **kidneys** are bean-shaped organs. They filter blood to remove extra water and waste in urine (wee). Most of us have two kidneys. They are on either side of our spine (backbone), near the bottom edge of our ribs at the back.

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 pelvis.

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.

» **More information about risks and complications**

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.

» **More about matching**

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 you 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.

» More about preparing for a kidney transplant

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, or sometimes in the middle, for example in very young children. 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

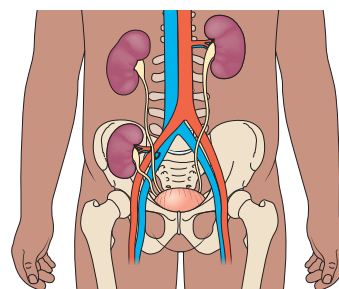


Illustration of where a transplanted kidney sits

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.

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.

» [More about after the transplant](#)

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.](#)

» [Supporting your child through a kidney transplant](#)

Risks and complications

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

Complications immediately after operation

Your child's transplant team will minimise these risks and monitor for any warning signs, so problems can be treated as soon as possible.

- **Bleeding** – occasionally, children bleed more than usual during the surgery and lose a large amount of blood. Some children need a blood transfusion to receive new blood from a donor; some may need to go back to the operating theatre to stop the bleeding.
- **Difficulty breathing** – occasionally, children are unable to remove the large amounts of fluid given during the surgery, and this may cause problems breathing. These children are usually treated in the paediatric intensive care unit.
- **Infection** may occur in one of the 'lines', in the urine, in the chest or in the wound. Steps are taken to reduce the risk of an infection, but if an infection does occur, children can take medicines that treat the infection.
- **Seizures** (also called fits or convulsions): very rarely, children have seizures after transplantation, though this is more likely in those who had them before. If this happens, children can take medicines that treat the cause of the seizure.
- **Thrombosis (blood clot)** – occasionally, if a blood clot is large, it can block the blood flow to the kidney.
- Sometimes the **ureter** (the tube between the kidney and bladder) is damaged and urine may leak.
- **Delayed bowel function** (not doing a poo) – sometimes, children will not be able to empty their bowels (do a poo) for a short time after surgery. This is because their bowels might 'go to sleep' during the surgery. If this happens, the bowels will usually 'wake up' naturally. The transplant team will check for signs of delayed bowel function, and treat it if needed.
- **Operation** – like all surgery, kidney transplantation has a risk of death; however this is extremely unlikely.

Delayed graft function

The transplanted kidney may take a few hours or a few days – or sometimes longer – before it starts working. This is called **delayed graft function**. We often say the kidney is 'asleep' and that we expect it to 'wake up' after it has recovered. This happens to 1 in 12 kidneys overall, but is more likely in children with a transplant from a deceased donor, especially if it is from a donor where the kidney was removed after the heart had stopped beating. (See **Deceased donors** for more information.)

Your child's transplant team will check the kidney function and blood supply after the operation. Some children need dialysis before the new kidney starts working.

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When kidney transplant does not work

Sometimes, the kidney transplant does not work properly. Your child's transplant team will look for any signs that the kidney is not working properly. This may happen for several reasons, which are described below.

If the kidney transplant fails, this is called **graft loss**.

Primary non-function (no function after the operation)

A few kidney transplants do not work because there is too little blood going into the new kidney. As with all organs, the new kidney needs plenty of blood flowing into it. This may be due to a **blood clot** (when the blood forms clumps). Smaller children are at higher risk of a blood clot.

Medicines called **heparin or aspirin** are used to stop the blood forming clots and reduce this risk.

Other kidneys may never work because they have been starved of oxygen for too long. This can be because of the events leading to donation or because there is too much time between taking the kidney from the donor to implanting it.

Complication of medicines

The anti-rejection medicines, or immunosuppressants, which need to be taken to reduce the risk of rejection may also cause problems. In particular, two medicines – **tacrolimus** and **ciclosporin** – can cause long-term effects on the kidney in some children, and may cause a condition known as interstitial fibrosis and tubular atrophy (IFTA). If this happens, your child's doctor may change his or her medicines.

Original disease comes back

Occasionally, the original disease that caused kidney failure comes back in the transplanted kidney. This may be the case with specific diseases, including:

- **Focal segmental glomerulosclerosis (FSGS)**
- **Membranoproliferative glomerulonephritis (MPGN)**
- **Atypical haemolytic uraemic syndrome (atypical HUS)**
- **IgA nephropathy**
- **Systemic lupus erythematosus and vasculitis**

Sometimes, the disease in the transplanted kidney is less serious than before, though your child will need to be monitored and may need further treatment. It does not always affect the kidney function. Occasionally, it can cause graft loss.



Rejection

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. Parts of the **immune system** can find, and destroy, foreign things, such as germs or other people's **cells**, which are the tiny living parts of the body. This is called **rejection**, and is the major complication of kidney transplantation.

To reduce this risk, your child's transplant team will have tried to find a close match between your child and the donor, and your child will take a combination of medicines that is right for him or her. If children forget or choose not to take the anti-rejection medicines, their bodies are likely to reject the transplanted kidney. **Adolescents or teenagers have the highest rates of kidney transplant loss of all age groups (including adults) – this is thought to be due to not taking the medicines as prescribed.**

Rejection may be sudden (**acute**) – there may be one or more episodes, or it may occur over a longer period of time.

Symptoms and signs

Many children do not have symptoms of rejection. Occasionally children experience:

- fever
- pain or tenderness around transplanted kidney
- blood in their urine (haematuria)
- reduced urine output
- tiredness/feeling unwell.

Tests

Your child will have blood and urine tests after the operation to check how well the new kidney is working. The amount of **creatinine** in his or her blood will be measured. This is a waste product in the blood, which the kidneys filter. A high amount of creatinine may be a sign of rejection.

Some children will need an **ultrasound scan** and a **biopsy of the transplanted kidney**, to confirm the problem.

Treatment

Early rejection can generally be successfully treated by changing medicines.

Rejection that occurs after 6 months or more since the transplant is much more difficult to treat, particularly if the rejection is due to your child not taking his or her medicines correctly.

Unfortunately, sometimes kidney transplants stop working because of rejection. If the new kidney does not work – or stops working after time – your child may need to start dialysis. Your child will be considered for another transplant.

Infections

All transplant recipients need to take anti-rejection medicines (called **immunosuppressants**), which make the immune system less active. This means they are at higher risk of getting infections caused by germs such as bacteria and viruses. Some of these are minor, but may need treatment with antibiotic or antiviral medicines. Others may be more serious.

CMV and EBV

Cytomegalovirus (CMV) and **Epstein-Barr virus (EBV)** are viruses that each cause a glandular fever-like illness in people with healthy immune systems. These people may have symptoms of glandular fever, such as a fever (temperature above 38°C), sore throat and tiredness, but they often get better after a few weeks. The virus does not leave the body, but rather stays in a dormant state – which means it is not active. These people are now 'immune' to the virus, and so cannot get re-infected with the virus.

In people whose immune system has been suppressed – such as when taking anti-rejection medicines – these viruses can cause more serious illness. Your child will be tested to find out if whether they have already been infected with CMV and/or EBV. If your child has not previously been infected with these viruses, he or she may be at a higher risk of getting ill if he or she receives a kidney from a donor who had been exposed to CMV and/or EBV. If your child has become 'immune' to CMV and/or EBV from a previous infection, then he or she is at a lower risk of getting ill from these viruses.

- **Cytomegalovirus (CMV):** for CMV, your child may be given a low dose of an antiviral medicine to protect him or her against getting this infection. If your doctor thinks that your child may be ill, he or she may be tested for CMV infection. Your child may be given a higher dose of an antiviral medicine that will kill the virus.
- **Epstein-Barr virus (EBV):** there is *no* effective antiviral treatment for EBV. Your doctor will test for EBV infection during your child's routine blood tests for a period after the kidney transplant. If your doctor thinks that your child may be infected with EBV, he or she may need to reduce the dose or stop some of the anti-rejection medicines. This will help your child's immune system to fight the infection.

BKV

The BK virus (BKV) is a commonly occurring virus. It is thought that over 80% of the population have been infected with the BK virus. However, it is very rare for these people to have any symptoms. People with healthy immune systems can show some symptoms – known as **primary BK infections** – including mild chest infections or fever (temperature above 38°C).

After a primary BK infection, the virus tends to hide itself in the kidneys or urinary tract, where it stays for the rest of a person's life. For most people this virus will remain there in a dormant state – which means it is not active. In people whose immune system has been suppressed – such as when taking anti-rejection medicines – this virus

can activate and may cause serious complications (**BKV nephropathy** or **BKVN**), including loss of graft (kidney) function and, in a small number of individuals, graft loss (failure of the new kidney)

Your child will have a **blood test** and a **urine test** if their transplanted kidney is not working properly, and a BKV infection is suspected. Some centres screen transplant patients for this infection, with regular urine tests. At present, there are some treatments that have been used with variable success but *no* specific antiviral treatment for a BKV infection. If your child has a BKV infection, he or she will probably need to reduce the dose of anti-rejection medicine (immunosuppressant), or may also need to change the type of immunosuppressant. This will help the immune system to fight the infection.

Other long-term complications

Obstruction to flow of urine

Sometimes there is blockage that affects how urine is drained.

Problems with blood vessels

Transplant renal artery stenosis (TRAS) may happen some time after transplantation. It means that the **renal artery**, the blood vessel that carries blood into the kidney, becomes narrower. This means that less blood can get into the kidney, and may cause high blood pressure and increase the risk that the kidney does not work.

High blood pressure

Some children have high blood pressure (**hypertension**) after transplantation, even if they did not have it before the surgery. This may happen because of TRAS or medications such as steroids. If this happens, your child may need to take medicines that control his or her blood pressure.

» [Read more in the infoKID topic Hypertension](#)

Cancer – including skin cancer

There is a slightly increased risk of **cancer**. Very occasionally, this is through the donor – however, this is very rare, as the medical histories of all prospective donors are carefully checked.

Transplant recipients have a much higher risk of **skin cancer** than the rest of the population. Protect your child's skin from strong sunlight by dressing them in long-sleeved tops and trousers and a hat, and using high-factor sunscreen (at least SPF 30).

PTLD – a type of cancer

Post-transplant lymphoproliferative disorder (PTLD) is a type of cancer that happens in about 3 in 100 kidney transplants in children. Your child's healthcare team will check for signs of PLTD at follow-up appointments. These include symptoms of nausea (feeling sick), diarrhoea or weight loss. If PTLD is suspected, your child may need a **biopsy** to help with the diagnosis. A tiny piece of an affected organ or lymph node is removed from the body with a needle and examined under microscopes.

Reducing or stopping the immunosuppressants often successfully treats PTLD. A few children need **chemotherapy** – much stronger medicines, to treat the cancer.

This is often related to EBV virus. Sometimes donors have this virus in their blood because they previously had an infection. It can also reactivate in a child who has previously had EBV, although many children have not yet been exposed to the virus.

Diabetes

Diabetes is a disease in which the body is not able to remove sugar in the blood after a meal. This is a rare side-effect of treatment with **tacrolimus** and **prednisolone**, medicines that need to be taken after transplantation. Sometimes, this can be successfully treated by changing the medicines. Occasionally, children need to take insulin, a medicine that is injected under the skin, for a long time.

Rejection

Rejection of the transplanted kidney happens because the immune system recognises it as 'foreign' tissue, and tries to reject or destroy it. To reduce this risk and increase the chances of a successful transplant, your child's transplant team will try to find a close 'match' between your child and a donor.

Your child will need some tests to find out information about certain 'markers' on his or her cells. These are added to a large database (on a computer), held centrally by the National Health Service Blood and Transplant. This helps to find a suitable donor – someone whose markers are closely matched with your child's.

Matching donors and recipients

Children are likely to need more than one transplant in their lifetime, and the better matched the first transplant, the easier it will be to match a second transplant. It is important to have as good a match as possible.

Matching is based on several things. The two main concerns are: blood group and human leukocyte antigens (HLAs).

Blood groups

Our **red blood cells**, one type of living cell in the body, belong to a **blood group**. This is based on whether or not we have certain substances on our red blood cells in the blood. 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.

The following table shows compatible blood groups.

Table 1: Compatible blood groups

Your child's blood group	Compatible blood group of donor
A	A or O
B	B or O
AB	A or B or AB or O
O	O

Tissue type - HLAs

We each have a **tissue-type**. This is based on 'markers' or proteins that are found on the surface of all cells in the body. These 'markers' are determined by our **genes**, and inherited from our mother and father.

Some of these protein 'markers' are **human leukocyte antigens (HLAs)**. These proteins are part of the immune system, and help the body to tell the difference between our own tissues and foreign substances.

Our own combination of antigens is on cells throughout our body. Half of the antigens come from our mother, and half from our father. This means that our tissue-types are more likely to be similar within a family.

When a donor and a recipient do not have the same antigens, the recipient's immune system recognises a transplanted kidney as foreign, and so may try to reject it. The closer the match, the lower the risk of rejection.

HLAs and mismatches

There are many possible combinations of antigens, 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.

Only 3 pairs of antigens are used when matching donors and recipients. These are labelled with the letters: A, B and DR. We understand that our immune system reacts most strongly to DR. For this reason, the transplant team tries very hard to find a complete match for DR antigens.

» Read more about matchability scores in Kidney transplant - deceased donor

Although it may seem confusing, when talking about the specific antigens, transplant teams talk about mismatches rather than matches. This is because it is mismatches that allow the immune system to recognise the kidney is from another person, leading to rejection.

For children having a deceased donor transplant, it is especially important to have a close match.

- A level 1 match (previously known as a **full-house match**) means there are no mismatches between the A, B or DR of the donor and recipient. This is the closest match, but is very difficult to find. It only happens in about one in ten kidney transplants in children.
- A level 2 match (previously known as a **favourable match**) is a less close match, but still a good match for a deceased donor transplant. This means there are no mismatches against DR and not more than one mismatch each between A and/or B. Between 2003 and 2012, half of the children having kidney transplants in the UK had a level 2 matched kidney.
- For children having a living donor transplant, it is acceptable to have a less favourable match.

In recent years, just over eight out of 10 children receiving deceased donor transplants have received either a level 1 or level 2 match. The others have less well-matched transplants. This is because their tissue type was uncommon and/or they had to wait a long time for a suitable donor.

Antibodies

Antibodies are part of the immune system. They are made especially to fight specific foreign substances, such as germs, that enter the body. In organ transplantation, and after **blood transfusion** (receiving blood from a donor), the recipient's body makes antibodies against the mismatched antigens on the donor's organ or blood. These antibodies may last for life and may prevent a repeat transplant with the same mismatches.

Preparing for transplant

Transplant team

Your transplant team will support you and your child before, during and after transplantation.

- **Transplant nurse (or coordinator):** a nurse who is experienced in kidney transplants in children, will give information and support before, during and after your child's transplant.
- **Paediatric nephrologist:** your child will continue to be looked after by the paediatric nephrologist, a doctor who treats babies, children and young people with kidney problems, and may be in a hospital or clinic.
- **Transplant surgeon:** you will have the opportunity to meet with the transplant surgeon, who manages the operation, before and on the day of transplantation.
- **Play specialist:** your child can meet with a play specialist, a professional who uses dolls and other toys to help your child prepare for the tests and operation.
- **Renal psychologist or counsellor:** you and/or your child may meet with a renal psychologist or counsellor, who supports you and your family, especially with emotional stresses and strains of looking after a child with kidney disease.
- **Renal social worker:** a professional who supports you and your family, especially with any concerns about money, travel and housing related to looking after your child with kidney disease.
- **Paediatric dietitian** – a professional who advises what your child should eat and drink during different stages of a kidney condition

Tests

Your child will need many tests to make sure he or she is ready for a transplantation. 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 established renal failure. Your child will need to continue going back to the unit for further tests while he or she waits for the transplant – sometimes up to a year or longer.

Blood tests

Your child will need a series of blood tests. A small amount of blood will be taken from a vein, using a needle and syringe. A special gel or cream can be used to help your child stop feeling any pain.

These give information about the following.

- **Blood group and tissue typing** – as described in Matching.
- **Serology** – this test checks whether your child has immunity to certain diseases, which means they will

usually not get ill again with these diseases. – The first time we are infected with a particular virus, which causes a disease, our body's immune system makes antibodies to fight it. The next time we are infected with the virus, our body can fight it more quickly so we do not get ill. For transplants, blood tests check for immunity to the following: measles, mumps, rubella, chicken pox (varicella), CMV, EBV, hepatitis B, hepatitis C and HIV.

- **HLA-tissue-type and antibodies** (see page 10).

Imaging tests

Your child will need some imaging tests (scans). These use special equipment to get images (pictures) of the inside of his or her body.

- **Ultrasound scan** – looks at the shape and size of the kidneys and other parts of the urinary system. A small handheld device is moved around your child's skin and uses sound waves to create an image on a screen. An ultrasound scan may also be used to check the blood vessels in your child's neck, abdomen (tummy area) and groin to make sure that the blood is flowing through them correctly.
- **Echocardiogram (ECHO)** – looks at the heart, also using ultrasound.

Occasionally, other imaging tests are needed.

Electrocardiogram

An **electrocardiogram** checks whether your child's heart is working well, or whether there are any problems with his or her heartbeat. Sticky pads are placed on your child's chest, and a machine measures the normal electrical activity.

Urodynamics

If your child has a history of bladder problems or **vesicoureteral reflux (VUR)**, he or she may also need urodynamics. These tests check how well the bladder is working.

Vaccines

It is important that your child has **vaccinations** (immunisations) against certain diseases. These include all the normal childhood vaccines plus chicken pox – if he or she has not already had this illness – hepatitis B and sometimes BCG (for TB).

Your child's doctor will need to check that he or she has developed antibodies against many of these infections, particularly:

- measles
- rubella
- chicken pox
- hepatitis B.

Live vaccinations must be completed at least one month before transplantation, or three months for the BCG vaccine.

Coming to hospital

You will be told when your child needs to come to the hospital – this depends on whether your child will have a live 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 to stay at or near the hospital.

Some children will need dialysis just before the transplant, on the basis of the blood tests (read more below).

Tests on the day of transplant

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 before the operation, and because these make the immune system less active, your child would be less able to fight the illness.

Blood tests

More samples of your child's blood will be taken for the following.

- **Blood clotting** – this test is used to find out whether the blood is clotting properly. Clots form in the blood to heal a wound, such as a cut in the skin, and it is important to know that your child's blood will clot as expected after the surgery.
- **Electrolytes** – to check the blood potassium is not too high and to check the acidity of the blood.
- **Serology** – this test, which checks for immunity to illnesses, is repeated.

- **Group and save** – a small sample of your child's blood is stored to be used in the rare event that your child needs a blood transfusion (if they have heavy bleeding). The hospital will be able to find out your child's blood group, so that they can get the right type of blood from a donor.

Immunological crossmatch

The **immunological crossmatch** tests for any reaction between a sample of your child's blood and a sample from the donor. The result can take up to four hours. If there is no reaction – if the result is 'negative' – the transplant can take place.

In some cases, a virtual crossmatch is done instead. This is often done for deceased donor transplants, especially from **donors after circulatory death (DCDs)** – when the heart has already stopped working), because the surgery needs to be done more quickly. Your child's doctors will look at earlier blood test results for any antibodies that might attack the transplanted kidney.

Preparing for a transplants: Read more about electrolytes

Electrolytes are important chemicals in the body. We need the right balance of these to stay healthy. Some important electrolytes include the following:

- **sodium** helps balance the amount of water in the body
- **potassium** is needed for the muscles, including the heart muscle, to work properly
- **bicarbonate** balances the amount of acid in our body, or the **pH balance** (also called the acid–base balance)
- **phosphate** is important for bones, teeth and muscles
- **calcium** is important for bones and teeth, helps blood to clot and also helps the muscles, including the heart muscle, to work.

After the transplant

Medicines and infection

After your child's kidney transplant, he or she needs to take medicines. These include **immunosuppressants**. These reduce the risk of his or her new kidney being rejected, but they also weaken the body's resistance to infection.

Your child has a greater risk of getting infections. This includes common infections such as the cold, as well as urine and chest infections. It is important to let your transplant unit know if your child is unwell with symptoms of fever, cough or diarrhoea and vomiting. Your child may be more ill than usual, or for longer, with an infection.

Safer eating

Because children taking immunosuppressants are at greater risk of infection, they need to take special care to avoid infection from food.

» [Read more in the infoKID topic - Safer eating after a kidney transplant](#)

Healthy eating

Before a kidney transplant, many children have restrictions on what they can eat and drink – for example, much less of the minerals potassium and phosphate, which are found in many foods. They may also have a poor appetite, feel sick or vomit. Some children use a **feeding device** – some or all of the nutrition they need to grow and develop can be given through a tube or button.

After a kidney transplant, most children feel better and are able to eat a diet that is more varied. Some children need to continue with tube feeding for a while until their appetite improves. While children are taking **steroid** medicines, especially for the first few months when the dose is high, they may feel more hungry than usual.

It is important that your child has a healthy and balanced diet – and that he or she avoids eating too much, and limits the amount of fat, sugar and salt.

» [Read more in the infoKID topic - Healthy eating after a kidney transplant](#)

Fluids

Before a kidney transplant, many children need to restrict their fluid intake – drinking less water and juice and eating fewer foods with a high water content, such as soups.

After a kidney transplant, your child will need to drink more fluids. He or she may be given a minimum amount of fluid to drink each day.

Follow up appointments

All children need follow-up appointments at the hospital or clinic, to check for any health problems. These will continue for the life of the kidney transplant and beyond.

It is important to go to these appointments. You will also have the opportunity to ask any questions. At these appointments, your child may have:

- his or her height and weight checked
- a physical examination
- **urine tests** – to check for blood, protein and other substances in his or her urine
- **blood tests** – to check the function of the new kidney, and levels of the immunosuppression treatment
- his or her blood pressure measured.

If your child has any problems with the transplanted kidney, a **kidney biopsy** may be recommended. This can give more information about what is causing the problems. It is usually done on a single day. Initial results are available from 1-3 days but more detailed analysis may take further time. A tiny piece of the new kidney is removed from the body with a needle, and examined under microscopes. Special medicines are used so your child does not feel any pain and can sleep through the procedure.

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 how to help manage and live with a kidney transplant.

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.

Support from the transplant team

Your child's kidney transplant team is there to help you. Some of the ways you and your child can get further support include the following.

- **Education:** your child's schooling may be interrupted, especially if your child has to go to the hospital frequently for tests, and around and after the operation. Your hospital can arrange for a teacher to give lessons.
- **Money:** A renal social worker may be able to help you access any financial benefits from the government that you are entitled to.
- **Holidays:** preparing for a transplant, waiting for a suitable kidney to become available, and the many follow-up appointments and after care needed in the months after the operation may make it more difficult to plan family time such as holidays or visiting other family members. Speak with your team about how to plan this time away so that it fits around your child's healthcare needs.

Other families

Talking with parents and carers who have gone through similar issues can be a big source of support and information. Ask your child's transplant team about meeting with other families whose children have

undergone a kidney transplant.

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

Transition to adult services

Children who have a kidney transplant will need life-long care to look after their new kidney. They may need dialysis or another transplant in future years.

When your child reaches adolescence, he or she will prepare to transfer (move) from paediatric services (for children) to adult services. The timing is different for each person – though many will start being looked after by an adult nephrology unit by the time they are 18 years old.

Grants

Financial grants are available from the BKPA for those on low income.

Further information

This is the end of the general information about kidney transplantation. If you would like to read more about kidney transplant and other topics related to kidney conditions, tests and treatment, you can find a list of topics covered on the infoKID website at 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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