



NHS

Great Ormond Street Hospital for Children NHS Foundation Trust: Information for young people and families

# Growing up after a kidney transplant

If you had a kidney transplant many years ago, you may have been too young to understand why you needed one and what impact it would have on your life as you are growing older. This information sheet explains about kidney transplants in general and the things you'll need to think about in the future. If you have any questions, please feel free to ask the doctor and/or nurse who looks after you. Our contact details are at the end of this information sheet.

## What is a kidney transplant?

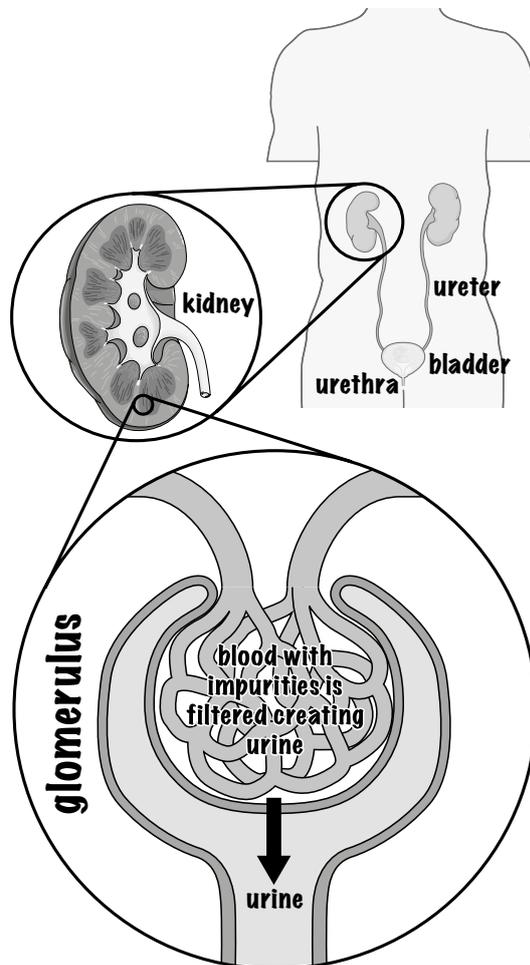
A kidney transplant is where a kidney is removed from the person donating it and put inside the body of the person receiving it. Kidney transplants are required when a person's kidneys aren't working well so they rely or will have to rely on dialysis to keep well. Dialysis can help by removing fluid and harmful substances from the body but it isn't a cure for kidney failure. It's a 'stepping stone' to keep someone well enough to have a transplant.

## How do the kidneys work?

The kidneys form part of the urinary system along with the ureters, the bladder and urethra.

Each kidney contains millions of tiny filtering units called glomeruli. As blood passes through the tubes in the glomerulus, waste products pass through the walls of the tubes to form urine. Blood cells and other things such as protein cannot pass through the walls because they are too big.

Once your kidneys have filtered the blood to remove waste products they produce urine. The urine flows from the kidneys down through the ureters to the bladder, where it is stored until we go to the toilet. It passes through another tube called the urethra to the outside when urinating (peeing).



# Why did I need a kidney transplant?

The most common reason for children and young people requiring a kidney transplant is that their kidneys did not develop properly in the womb. These problems are usually caused by how the kidneys are formed rather than an illness. Your kidney problem may have been diagnosed before you were born as some conditions can be picked up using an ultrasound scan during pregnancy. These are called 'congenital' problems and the most common type is referred to as dysplastic kidneys. It can also be associated with blockages or obstruction, and the most common obstruction is called posterior urethral valves, which only happens to boys. Illnesses causing kidney inflammation (glomerulonephritis) are another cause of severe kidney failure in children and young people who were born with normal kidneys. The most common type is called focal segmental glomerulosclerosis (FSGS), which is a type of nephrotic syndrome and haemolytic uraemic syndrome.

The doctors will explain what caused your kidneys to stop working and why you needed a kidney transplant. We have produced information sheets about the most common causes of kidney failure, which are available from your medical team, the Pals Office or on our website.

# How did the surgeons do the kidney transplant?

You would have had the transplant operation under general anaesthetic so you would not have felt or remembered anything. The surgeon would have made an incision (cut)

either down the middle of your tummy or near your hip and put the new kidney inside your abdomen. They would then have connected up the blood supply to the kidney and attached the ureter. At the end of the operation, the surgeon would have closed the incision with dissolvable stitches and covered it with a dressing.

# Keeping your kidney healthy

There are key ways of keeping your kidney healthy – by drinking enough fluids, taking your medicines, keeping your check up appointments and having tests (such as blood, urine, ultrasound and urodynamic investigations). If you were young when you had your transplant, these things are probably second nature by now but they are just as important now you are older and will carry on once you move to an adult service.

## Fluids

It is important that you drink your daily quota as discussed with your doctors or nurses. If you are unable to reach this target or if you have excessive losses (such as vomiting or diarrhoea) then please contact us urgently.

## Medicines

The most important of these medicines are the ones that 'dampen down' your immune system to stop your body attacking your new kidney - these are called 'immunosuppressants'. Although we have a few patients on one or two medications, most patients are on more, but this depends on your kidney function and previous rejection episodes. You may be on other medications as well such as antibiotics to prevent or treat infections or anti-hypertensive medications if your blood pressure is high. We will give you information about all the medicines you are taking.





It is vital that you take all of your medicines at the correct dose at the right time. Not taking your medicines, could lead to serious illness and the loss of your kidney. In fact, the most common reason for young people losing a transplanted kidney is not taking the immunosuppressant medicines as prescribed and this happens to at least one patient at GOSH every year. If you are struggling with your medicine schedule, please talk to us sooner rather than later so that we can help you. You can come to GOSH to see us or we can ring you when convenient.

### **Check up appointments and tests**

You will continue to have regular check up appointments at GOSH for many years after your transplant and then at the adult kidney transplant service after transition. These appointments are vital to monitor how your kidney is working and your general health and well being. Missing just one appointment could have a serious impact on your kidney function. If you have any problems getting to an appointment, please let us know as soon as possible so we can re-book it.

## **Lifestyle issues**

When you've had a kidney transplant you should be able to have a normal day to day life. However, there are some things you might need to think about carefully as they could harm your kidney.

### **Food and drink**

You will need to keep hydrated by reaching your fluid target, which is a target amount to drink each day. Dehydration can damage your kidney so you must make sure you drink enough. Eating a balanced diet will help keep you at the right weight for your age

and size. Some of the medicines can increase your appetite so you may want to eat more and this may result in excessive weight gain. If you're worried about your weight, please talk to us. We can arrange a meeting with our dietitian to advise you.

### **School and college**

We know that you might not want to tell everyone in your life that you've had a kidney transplant, but it can be useful to let your school or college (teachers, tutors, lecturers) or employers know so that they can support you. It could be important in an emergency or if you need to sit out from particular games or sports. You may also need permission to leave class to go to the toilet. We are happy to speak to people at school or college if you want us to or if they have any questions.

### **Games and sports**

Please talk to the team before you start doing any new sports so we can check that it won't damage your kidney. We recommend that you avoid contact sports where you could get hit in the abdomen, such as rugby or judo. However, we suggest that you discuss this with us as we can supply kidney guards which can offer some (albeit limited) protection. If you are really keen on a particular sport, please talk to us about it so we can see what we can do to help.

### **Further education and jobs**

There is no reason at all why you shouldn't go onto college or university if you want and get a fulfilling job. Your kidney transplant may restrict your choices, as some employers may not think that you would be suitable due to your kidney transplant (especially physical jobs where there is a risk of blows to the abdomen). Please discuss your future plans with the transplant team and our adolescent nurse specialist

who both have plenty of information and contacts for further help.

### **Coughs, colds and infections**

The medicines you're taking help to stop your body fighting off your kidney but they also reduce your ability to fight off everyday infections as well. You might find that if you catch a bug, it lasts longer and you feel worse. If you think you've caught a bug, it's important to get the right treatment as quickly as possible. Your family doctor (GP) will be able to help and they can always call the team for advice if needed.

### **Immunisations**

We would have checked your immunisations before the operation and given you any you were missing. After the operation you should be able to have most immunisations although you should avoid the following ones:

- MMR (Measles Mumps and Rubella)
- BCG (Tuberculosis)
- Varicella (Chicken pox)
- Oral polio
- Yellow fever
- Oral typhoid

The immunisations that you usually have when you're a teenager, such as Human Papilloma Virus (HPV) and Meningitis C, are fine to have. We also strongly advise you to have the flu jab every year as flu can be harder to fight off if you're taking immunosuppressant medicines. If you are going abroad, please check with us before you plan your holiday and organise any jabs and medicines.

### **Holidays**

There shouldn't be too many restrictions on where you can travel but you might have to avoid areas where certain diseases are common, especially if you cannot have the immunisation against the disease. If you are planning to visit an area where

malaria is common, please talk to your family doctor (GP) first to find out which medications they recommend and then discuss with us as some anti-malarial medicines can react with your immunosuppressant medicines.

Make sure that you arrange travel insurance well in advance of travelling. Some insurance companies are reluctant to insure people who have had transplants, but the British Kidney Patient Association holds details of companies that might be able to help. Travel insurance covers the cost of any treatment you might need when you're abroad so is essential. In addition, you should carry a European Health Insurance Card if you are travelling within the European Union.

Wherever you go on holiday, even in the UK, we suggest you take a covering letter with you. This should include your medical history, requirements for drinking fluids and a list of medicines. When you travel, make sure you carry enough medicine to cover your holiday plus a few days extra and carry it in your hand luggage.

### **Skin care**

Your skin will be more likely to get sunburnt after transplant. This is a side effect of the medicines you are taking. Always protect your skin from direct sunlight and use a high protection sun cream (Sun Protection Factor (SPF) 30, at least but preferably SPF50 or SPF60). You should cover up with a long-sleeved top and a hat and stay in the shade during the middle of the day when the sun is strongest. This is just as important in the UK even though it doesn't often feel hot enough to burn.

### **Body image**

As we grow up, we all become more aware of our appearance and anything that makes us different to our friends. You will, of course, have a scar from





the operation near your hip. If you are concerned about the appearance of your scar, talk to us as there are various options to improve its appearance.

The medicines you take have certain side effects that might alter your appearance, for instance, hair thinning from MMF or acne and weight gain from steroids. Again, please talk to us as there are ways of managing side effects so that they are less troublesome. We also have a counsellor in the renal team who can talk to you about body image issues and ways of coping.

### **Cigarettes and alcohol**

We do not advise smoking at any point, especially after a transplant. The chemicals contained in cigarettes have various effects and we want you stay fit and healthy for many years!

While alcohol is unlikely to react with the medicines you're taking, you can get dehydrated when drinking alcohol. We suggest that you limit the amount of alcohol you drink after transplant and do not binge-drink. Vomiting if you've drunk too much alcohol is also a problem as it could make you dehydrated and you could vomit your immunosuppressant medicines. The main job of the kidneys is to filter out poisons, including alcohol, so drinking to excess puts an extra strain on your kidneys.

### **Body piercing and tattoos**

These are generally not advised due to the risk of infection through dirty needles. As you are taking immunosuppressant medicines, you will be less able to fight off infections if they occur. If you feel you want to have a piercing or tattoo, you should always discuss this with us and use licensed premises that are registered with the local health authority.

### **Sex**

Some boys have trouble getting and keeping an erection, even after transplant. There are various options for helping with erectile problems, so please discuss them with your doctor. If you are embarrassed, you can always ask to speak to a male member of the team. If you want to know more about sex and contraception, please talk to us.

### **Contraception**

Like any other infection, sexually transmitted infections (STIs) can be harder to fight off when you're taking immunosuppressant medicines. Always use a barrier method of contraception to reduce the risk. If you want to consider taking the pill, please discuss this with your doctor as some brands can react with your immunosuppressant medicines.

### **Pregnancy**

Many adult kidney transplant patients have gone on to have successful pregnancies with support from their Adult Renal Transplant team. However, it is important that any pregnancy is planned. You will need extra monitoring as some of the medicines you are taking could harm an unborn baby.

The new kidney has been positioned inside your abdomen so that it won't get squashed by your baby and natural childbirth should be possible. During pregnancy, you will need to be monitored more frequently than usual, due to the risk of urinary tract infections and high blood pressure, both of which might cause problems with your kidney. If you develop high blood pressure, your baby is likely to be delivered early.

## And finally...

Having a kidney transplant gives you the opportunity to live your life and achieve your goals but you need to look after yourself to keep well. Taking good care of your health through attending your appointments and taking your medicines will mean that nothing can stop you doing what is important to you! Remember if you have any questions or want to ask us about anything not covered in this information sheet, please contact us.

There are also various support organisations that can offer advice and support. The British Kidney Patient Association ([www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)) and the National Kidney Federation ([www.kidney.org.uk](http://www.kidney.org.uk)) can both provide information about life with kidney disease and transplantation. The Transplant Support Network ([www.transplantsupportnetwork.org.uk](http://www.transplantsupportnetwork.org.uk)) can offer support before and after transplant.

### useful numbers

Clinical Nurse Specialist – Renal Unit: 020 7813 8172

Adolescent Nurse Specialist: 020 7813 8541

### Notes

Compiled by the Renal and Adolescent Medicine teams in collaboration with the Child and Family Information Group

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