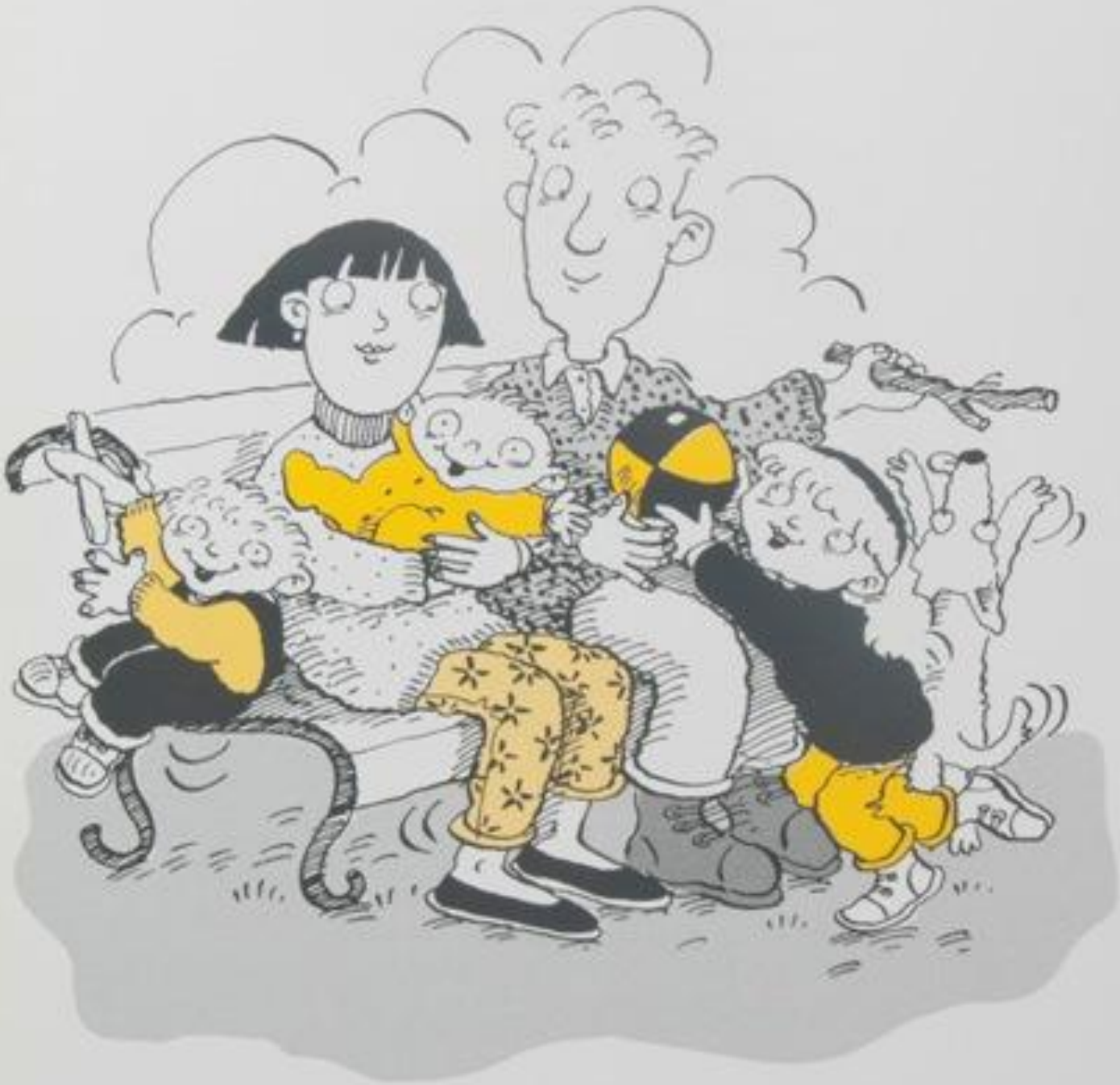
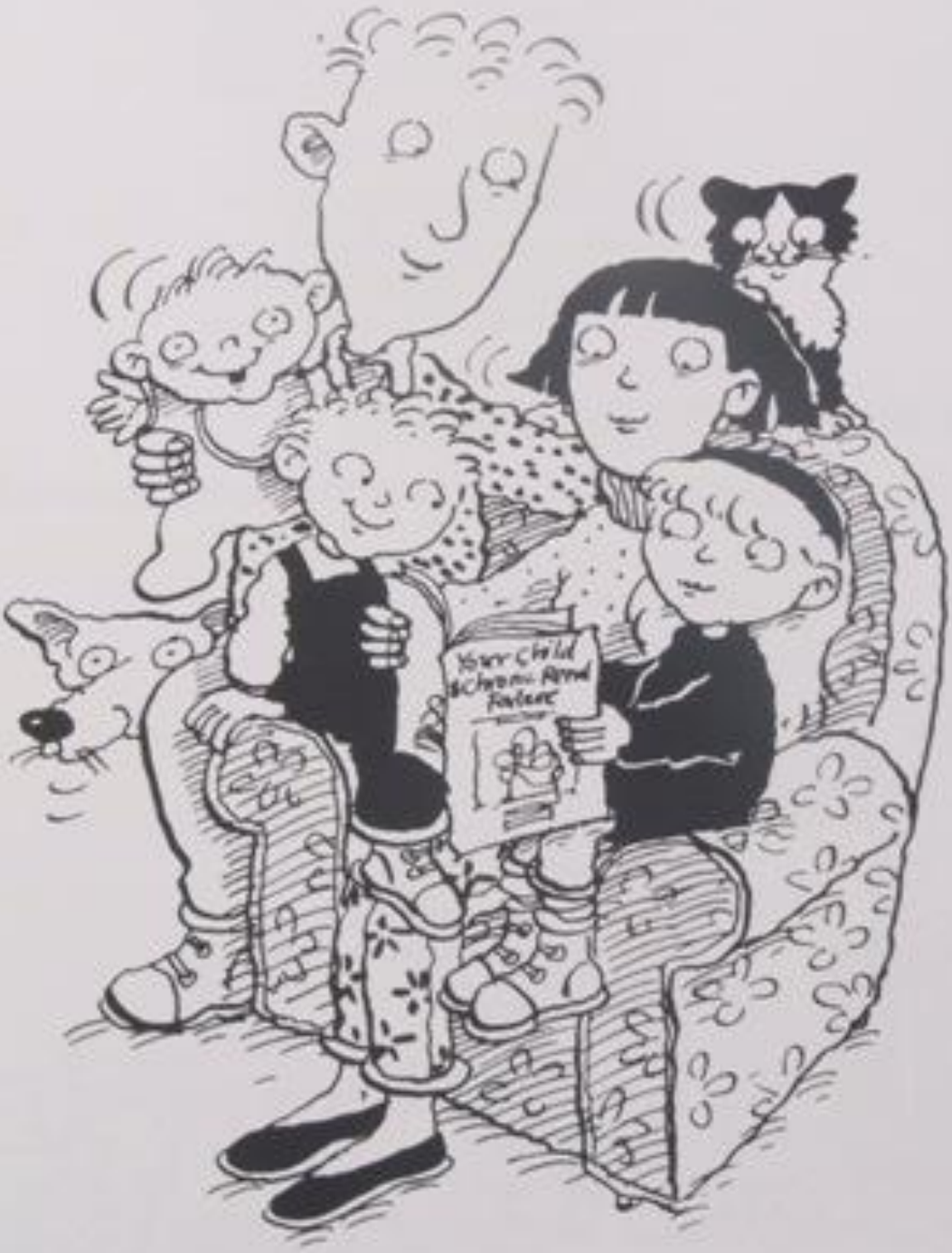
Kidney Transplantation in Childhood



A guide for families

contents

You may have already learnt some of the facts about kidney transplantation from the chronic renal failure booklet. This booklet gives more information about what happens before and after a kidney transplant.



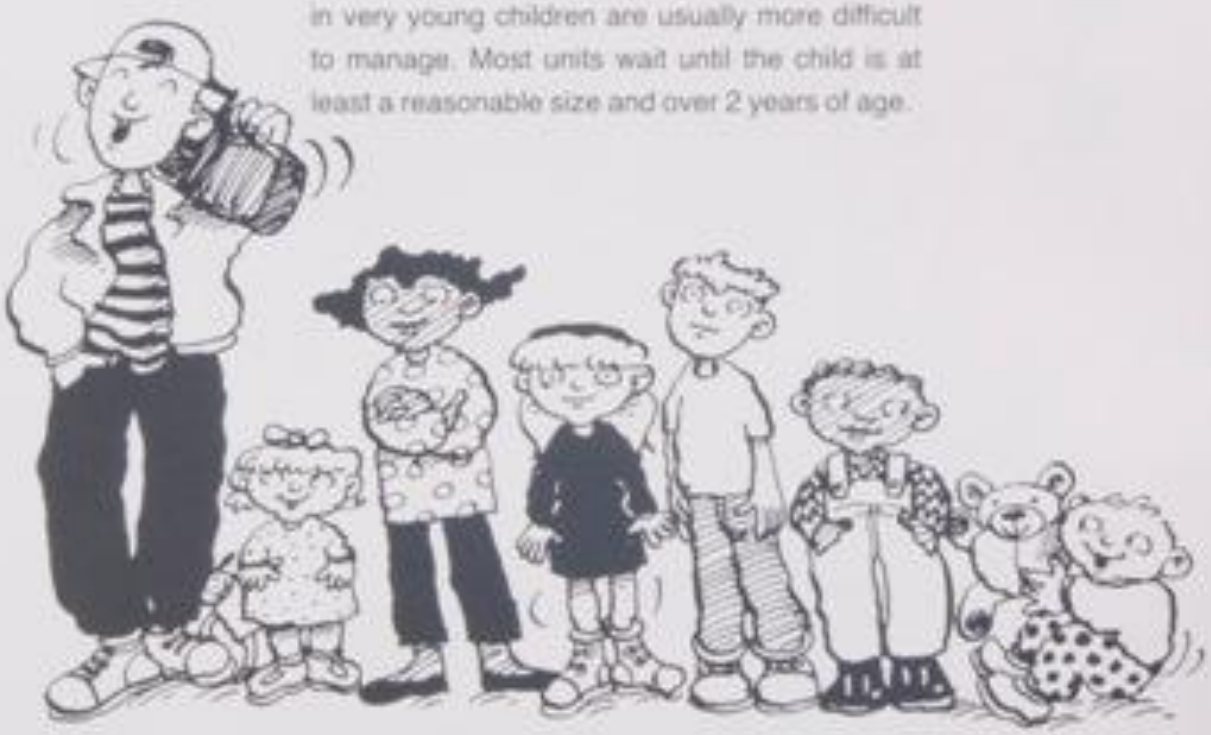
why is a transplant necessary?

Dialysis is only a **temporary** measure before a kidney transplant becomes available. Even if dialysis is doing well and keeping your child healthy, it is a renal transplant which offers the best **quality of life**. With a successful transplant there should be less disruption to family and school life. Diet and fluid restrictions should no longer be necessary.

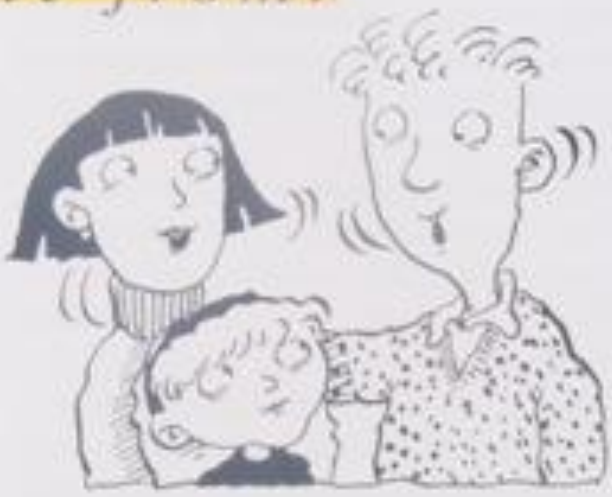
A kidney transplant may be considered **before** a child needs dialysis (pre-emptive transplant). This may be discussed with you by your kidney specialist (nephrologist) and transplant surgeon.

at what age do we consider a transplant?

There is no strict age limit but kidney transplants in very young children are usually more difficult to manage. Most units wait until the child is at least a reasonable size and over 2 years of age.



where does the transplant kidney come from?



A kidney may be donated by a family member. This is known as a **living related donor** transplant. For children this usually means a mother or father or exceptionally another relative. Before deciding to go ahead many tests are performed over several months to make sure the parent is healthy and a kidney is suitable. If going ahead transplant surgeons require a detailed physical and social assessment as there are many issues to consider.

The alternative is that the child receives a transplant from a person who has died in an intensive care unit and where the relatives have agreed to donate the kidneys. This type of transplant is known as a deceased donor kidney transplant.

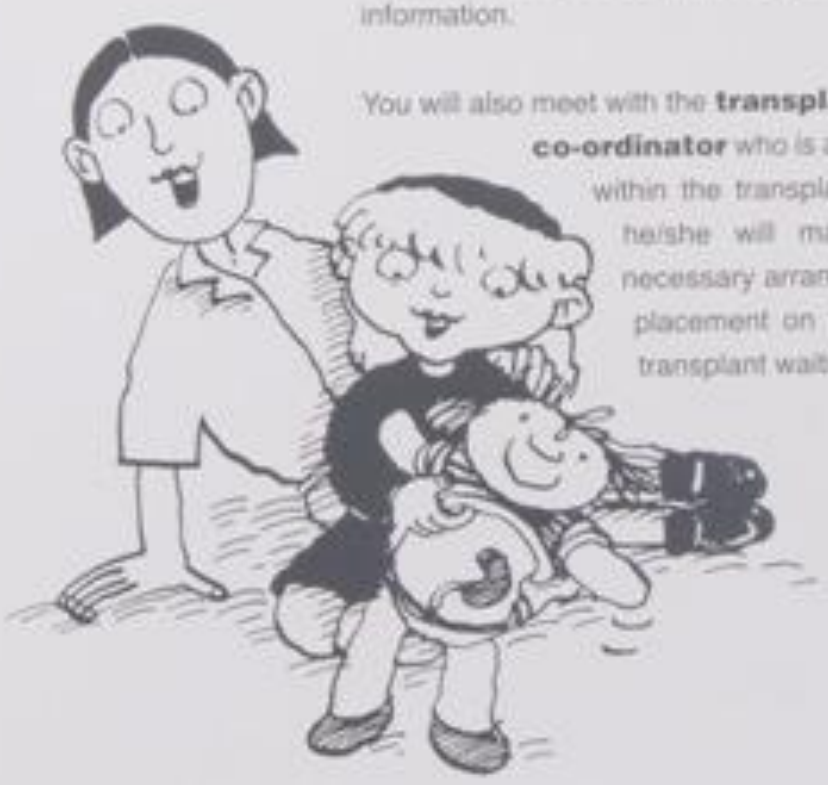
Where families opt for a deceased donor transplant or a living donor is not possible then the child's name is added to the national **transplant waiting list**.

what assessment is necessary?

Placement on the **transplant waiting list** follows discussion with the kidney specialist and transplant surgeon.

Preparation is very important for all the family and this will be carried out by the renal nurse and play specialist. Visits to the area where your child will be nursed after the operation will be arranged. Play therapy using dolls, videos and photograph albums of other children who have undergone a transplant may be helpful. It is important that your **child's questions and fears** are talked about as well as your own.

The **social worker** will also meet with the family to discuss important issues and other concerns which can be helped by discussion and information.



You will also meet with the **transplant co-ordinator** who is a key person within the transplant unit and he/she will make all the necessary arrangements for placement on the national transplant waiting list.

how are kidneys matched for transplantation?

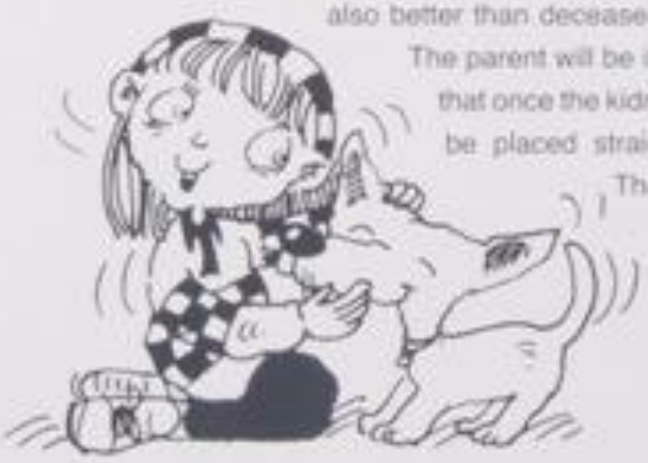
To be offered a kidney your child has to be of a similar **blood group** to the donor. We also aim to match the **tissue type** (or genetic make up) of the donor and your child (the recipient). The level of **antibodies** in your child's blood is also important.

what are antibodies?

We all have antibodies in our blood which can react against certain cells or tissue types. If your child has had previous transfusions or a previous transplant then the level of antibodies in the blood may be high. A high level of antibodies means that it may take longer to match a suitable kidney.

living related donor transplant

One of the major advantages of a living related donor transplant (LRD) from a parent to a child is that the operation can be **planned** for a certain day and time. The long term results for LRD are also better than deceased donor transplants. The parent will be in another theatre so that once the kidney is removed it can be placed straight into their child. The operation will be postponed if the child or parent are unwell.



if i don't have an LRD when will the transplant happen?

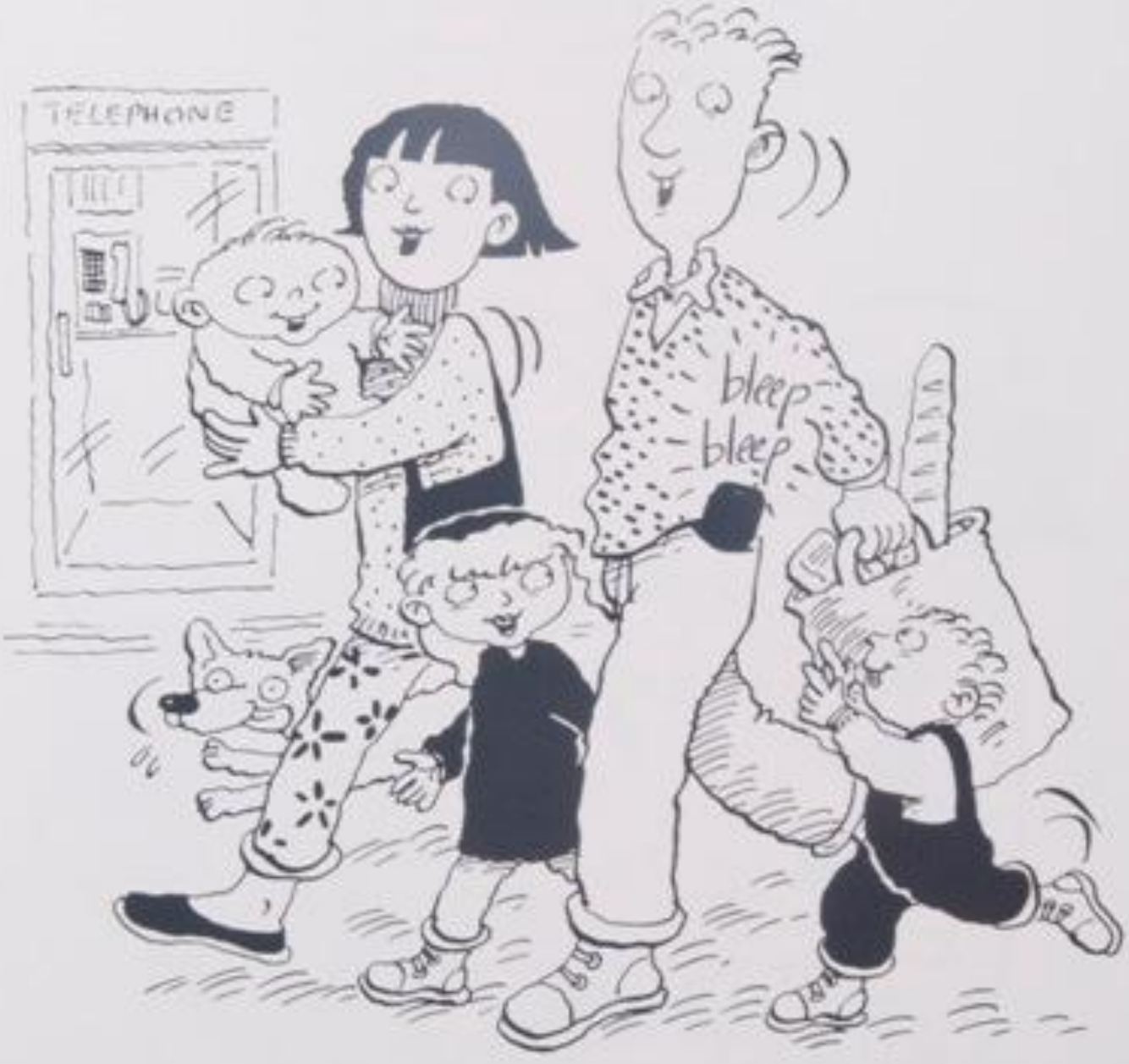
There is a large waiting list for kidney transplants which is held on a national computer based in Bristol. This does not function on a first come first served basis, but is a way of allowing a suitable matched kidney to be found. When the **match** between a donor kidney and your child's tissue type is suitable then he/she may be offered the kidney at any time. However, sometimes the wait can be quite long.

deceased donor transplant

You will be contacted by a member of the renal team if a suitable kidney becomes available. This may happen day or night so you will be asked to leave a **contact number** if you are away from home. Pagers can be provided if necesary but it would help if you have a mobile phone and other telephone numbers to contact you.

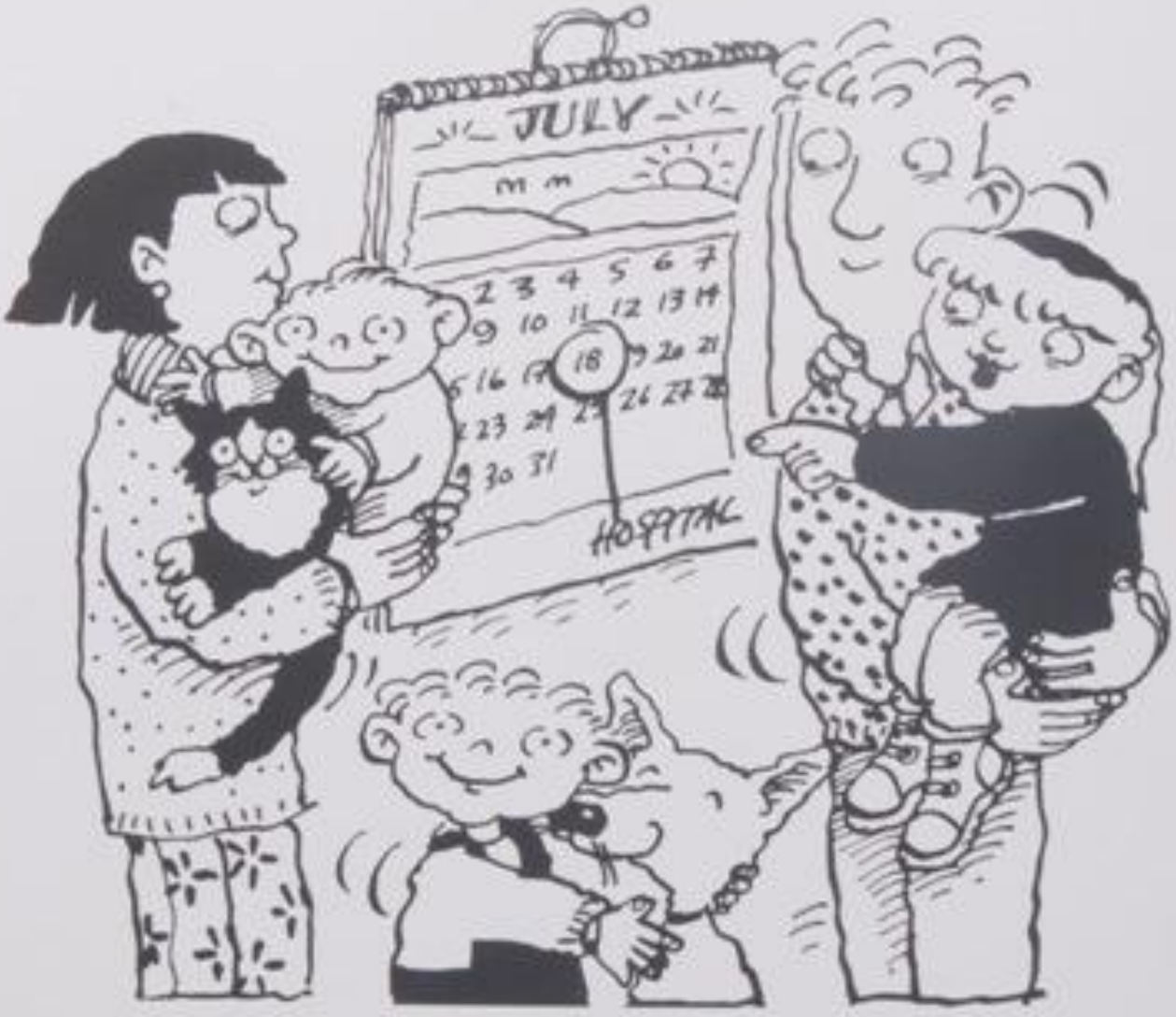
The operation can only go ahead if your child is well and not suffering from colds and other infections. You will be asked to come to the hospital as soon as possible as there are tests to be done before it is finally agreed for the operation to proceed.

You can be assured that the donor is always tested for the HIV (AIDS) and other viruses. We always look carefully at the match and it is possible for children to have a kidney from an adult donor.



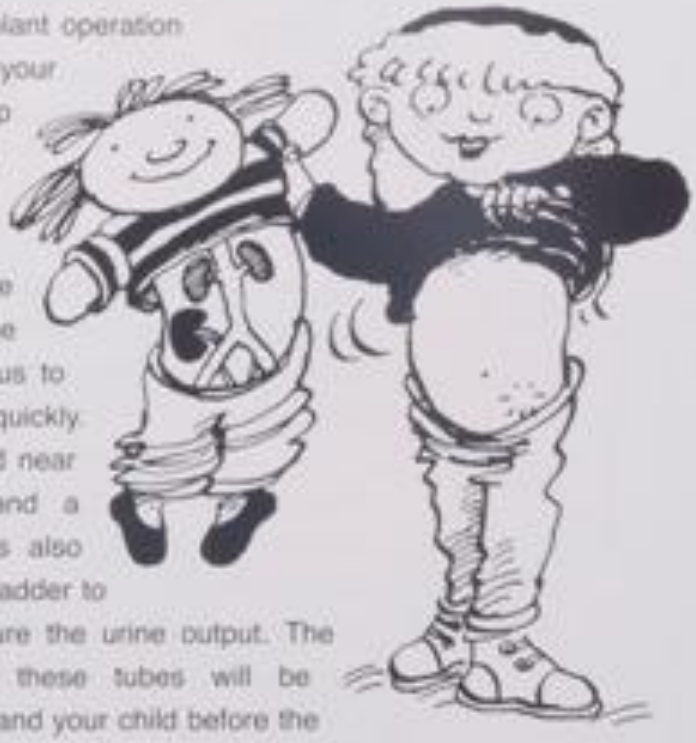
what does the transplant operation involve?

Routine blood tests and other tests will be done to make sure your child is fit for the operation. The operation may still be cancelled if there is a reaction between your child's blood and cells from the donor. This is what we mean by the term **positive crossmatch**. The operation is cancelled if the crossmatch is positive because the kidney will probably be rejected early.



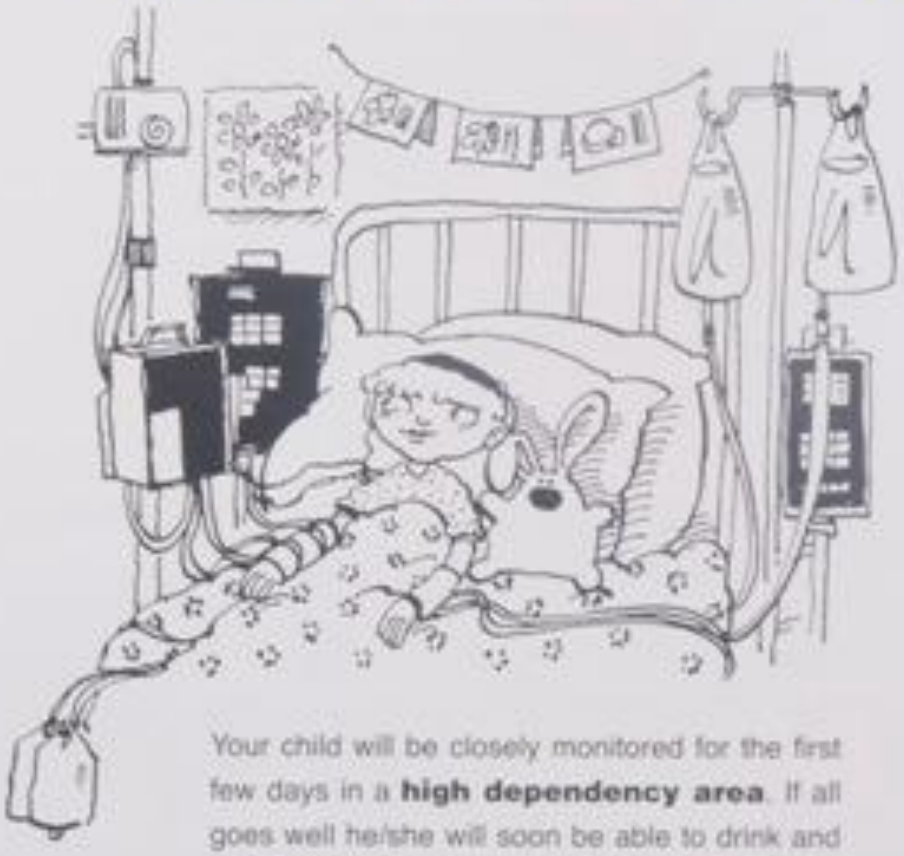
where is the kidney placed?

The transplant surgeon places the kidney low down in the abdomen to one side and usually outside the cavity containing the intestines and appendix. The appendix is **not** removed. The transplant kidney is placed low down on one side so that it can be joined to the major blood vessels going to the leg and also to avoid problems with the ureter leading to the bladder. The child's own kidneys, which are deep in the back, are only removed if they are causing problems.



Before the transplant operation starts and while your child is asleep (anaesthetised) a tube is put into a large vein in the neck to measure the pressure in the veins and allow us to give lots of fluid quickly. Drains are placed near the transplant and a tube (catheter) is also placed into the bladder to accurately measure the urine output. The reasons for all these tubes will be explained to you and your child before the transplant happens. If your child is very worried about tubes and needles then we might ask the clinical psychologist to help us prepare your child. Some children also have a nasogastric tube placed down the nose to help us to drain fluid off the stomach until the bowels are again working.

what happens after the operation?



Your child will be closely monitored for the first few days in a **high dependency area**. If all goes well he/she will soon be able to drink and eat normally. Any discomfort after the operation will be controlled by an infusion of pain killers.

The drain from around the kidney will usually be removed after two to three days but the catheters into the bladder may stay in place for five to seven days. If there are signs that the kidney is not working then a special scan may have to be arranged. For most people the transplant starts working immediately. Sometimes transplants take some time to work properly and dialysis may be needed in the meantime. This does not mean the transplant has failed as it can sometimes take a few days or even weeks for the transplant to 'wake -up'. This can be a difficult and worrying time and all members of the renal team will keep you closely informed of progress.

how long will my child be in hospital?

This will depend upon how your child recovers from the transplant operation. It may be ten days to several weeks depending upon how long the kidney takes to start working and whether there are any problems with rejection. Parents will be **welcome** to stay throughout this time. We appreciate that you may feel torn between your child in hospital, work and other family at home.

going home after the transplant

Before you are allowed home you will have some further teaching so that you can carry on monitoring your child's progress at home.

You may be asked to **record** blood pressure along with keeping an eye on the fluid intake and current drug treatment. **Regular visits** to the hospital will be necessary during the first few months (twice a week initially, then at least weekly) so that your child's blood can be tested regularly as one of the most important signs of rejection is a rise in the creatinine level.

what drugs are used after a transplant?

Powerful drugs known as **immunosuppressants** to prevent rejection are given in big doses at first and then gradually reduced with time.

Such drugs include **tacrolimus** (Prograf), **azathioprine** (Imuran), **mycophenylate mofetil** (Cellcept) and **prednisolone** (steroids). Many units use a combination of three immunosuppressant drugs. Occassionally additional drugs are used, such as **Basiliximab** or **Daclizumab** which are given by intravenous injection. The steroids used are corticosteroids and not the anabolic steroids abused by some athletes.

You should be aware that immunosuppressant drugs **are taken for as long as** the transplant kidney functions. It is important that immunosuppressive drugs are **NEVER missed** and are taken **as prescribed**. If drug doses are missed then rejection and damage to the kidney can occur at any time.

Contact the renal unit for advice if your child has diarrhoea or vomiting, or if you have any worries.

OTHER DRUGS

Nifedipine, **Atenolol** and **Enalapril** are **antihypertensive** drugs. They are used because there may be an increase in blood pressure after transplantation.

Aspirin is usually given for 6 - 8 weeks following transplantation to prevent thrombus (clot) formation.

Co-trimoxazole (Septrin), an **antibiotic** is used to help prevent infections in transplant patients. Septrin is usually given for the first 6 months after transplantation when patients receive high dose immunosuppressive drugs.

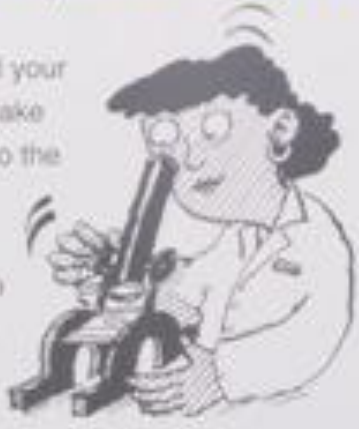
TRIALS

We are currently trying to discover the BEST combination of drugs to use after transplantation to minimise rejection and reduce side effects. Many units are participating in international studies of transplant drugs in children and you may be asked to join. We will ensure that full information is given to you.

what is rejection?

Rejection is the term used for an attack on the kidney by the body's own defences. Signs may include fever, reduced urine output, tenderness over the kidney, rise in blood pressure and feeling generally unwell. However many times we **suspect** rejection because of a rise in the blood creatinine level. If rejection is suspected then a **biopsy** of the transplant kidney may be needed. Rejection is usually treatable with increased steriods. Occasionally other long term changes are made to your child's immunosuppressants.

how is a biopsy performed?



The biopsy will be explained to you and your child. Using **sedation** (medicine to make your child sleep), a needle is placed into the kidney after an ultrasound scan has been performed. The tissue obtained can be examined under the microscope and can reveal what is going on within the kidney. This may be important information in the choice of treatment.

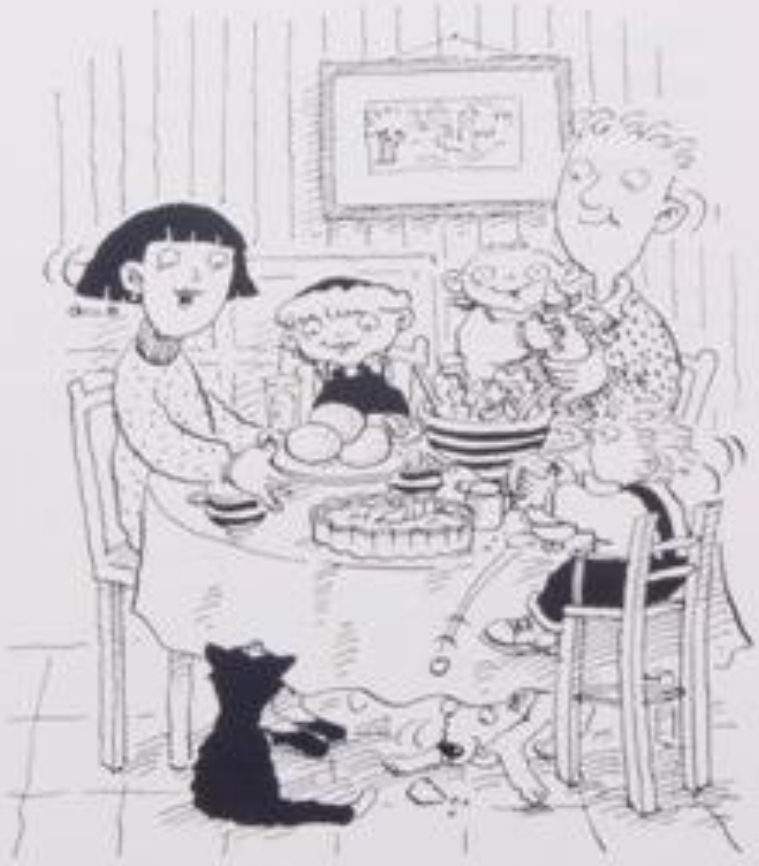
how long will the transplanted kidney last?

Unfortunately kidney transplants do **not** last forever. However, some patients have had their transplants for over twenty years. It is possible to return to dialysis if the kidney fails to await a further transplant.

is there a special diet after transplantation?

One of the great benefits of the transplant is that your child is likely to have a better appetite, and diet and fluid restriction should no longer be necessary. Those children who required supplements or overnight feeding beforehand should start to eat and drink again. **Weight gain** can be a problem after the transplant, especially as appetite is increased by steroids. A 'no added salt' diet is still recommended to help control high blood pressure. **A healthy eating diet** will be encouraged for all the family.

You will be given a short list of foods that should be avoided in the first 6 months after a transplant because of a risk of infection.



physical changes after transplantation

Initially weight gain and some fattening of the face is quite common but may not happen because the steroid drugs are usually reduced quickly after the transplant. Steroids can also cause an increase in spots or acne in the older child. Do ask for advice. Thinning of the hair may be a side effect of Tacrolimus, which usally settles.

removal of dialysis catheters after transplantation

These are usually removed about two to three months after a successful transplant. The procedure can usually be done as a day case admission under general anaesthetic. If your child has a gastrostomy button this can also be removed at the same time.

emotional well being

For the child this may involve coming to terms with changes in body image as well as changes in what they are able to do. Even though most changes will be for the better, they are still changes and the child may be more emotional during the time of adjustment. They may have other reactions such as bad dreams or changes

in behaviour. If these persist it may be helpful to ask for some help from the psychologist or social worker. Young people can talk confidentially to a youth worker.

Adults too have a period of adjustment. Having geared themselves up for transplant and coped with all that entails, they are often exhausted and thus find any additional problems difficult to cope with. They may also be prone to infections. Parents who have been kidney donors may experience low moods after the initial excitement of the transplant.

Brothers and sisters have also been through a traumatic time and need some additional care. They have had to tolerate some time without their parents and have had to deal with worries about their sibling. They may also feel a bit left out as their brother or sister has had increased attention.

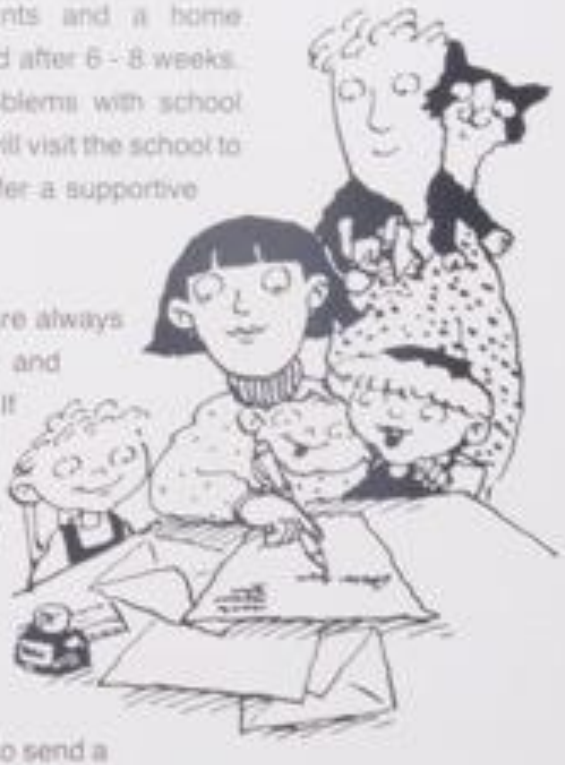
In general most problems can be helped by talking so if any of your family experience difficulties do consult the social workers or psychologist. If the kidney has come from a close relative (likely to be a parent) then emotions may run high at times. There could be an extended time of recovery given that two members of the family have had operations. This can put a strain on the parent who is well and looking after everyone else.

at home after the transplant

Taking medicine every day can become really tedious and at times, especially when your child is feeling worried or fed up about something, they may be tempted not to take their medicines. It is unlikely that you will notice any effects immediately although it will have an effect on the kidney

Recognise that your child may have problems which are making them unhappy and get some help. This is better than suffering kidney rejection.

If your child has lost some time off school then we will try to arrange to have work sent to the unit or home. Most children are ready to return to school in about 4 weeks. Return to school may be delayed if your child is on high doses of immunosuppressants and a home tutor can be requested after 6 - 8 weeks. As there may be some problems with school adjustment, team members will visit the school to explain the treatment and offer a supportive link.



Members of the renal team are always available to give you advice and support after the transplant. If the transplant is successful with time there will be a reduced contact with the unit compared to the days when your child was on dialysis.

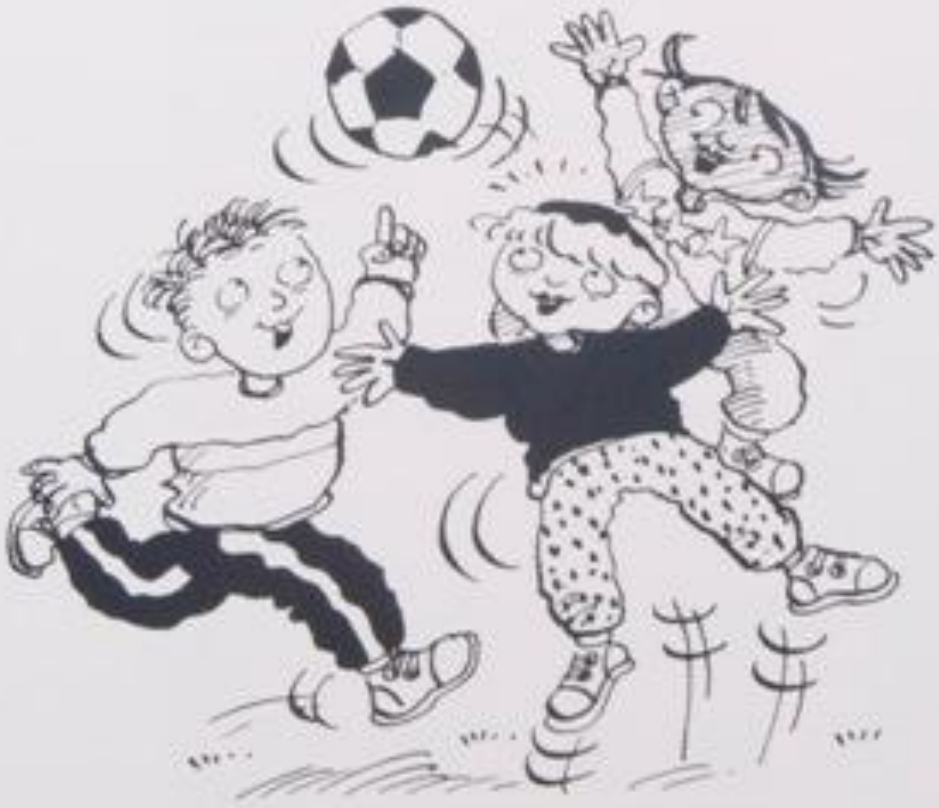
Many recipient families wish to send a letter of thanks to the donor family which is always well received. This may be written any time after the transplant operation. The letter usually expresses sympathy, thanks and a brief description of the child pre and post-transplant. First names may be used but the letters should remain **anonymous** with no surnames or addresses. The transplant co-ordinator will arrange postage and she/he or other team members are always willing to help you write such a letter.

are my child's activities restricted after a transplant?

We encourage as much physical exercise as possible. However, we do caution against a few sports such as rugby or martial arts as the kidney may be vulnerable to direct kicks or blows.

Your child can go **swimming** after the dialysis catheter is removed.

Every year there is a national event called the Transplant Games where children and adults who have had organ transplants compete. Your child is welcome to participate. Please visit www.transplantsports.org.uk for more details.



common questions

1. Can we travel or go on holiday when we are on the transplant list?

YES, however holidays abroad are not recommended. If you are more than 4 hours travelling away from the unit your child will need to be temporarily suspended from the national list.

2. After the transplant, how far can we go away on holiday?

If the transplant goes well, then after about three months a holiday anywhere in the UK could be planned. However, it will depend upon how frequent your child needs to be checked and whether we can make local arrangements for blood tests or check ups if these are necessary. Holidays abroad are also possible but should be deferred for 6 months to a year after the transplant until it is certain everything is going well with the transplant.

3. Should seat belts be worn in the car?

Although the lap portion of the seat belt may press slightly over the transplant area this does not harm the kidney. The wearing of seat belts is compulsory and always recommended.

4. Vaccinations and immunisations

When your child is taking immunosuppressant drugs then all live vaccines such as BCG (for tuberculosis) and live polio should be avoided. Vaccines made from dead bacteria may be acceptable, but always check with your nephrologist.

5. Which infections are a worry post-transplant?

Any infection after a transplant can be a problem as the immunosuppressive medicines needed to keep the kidney healthy also reduces the ability to fight infection. Chickenpox is a major concern if your child does not have antibodies. If your child is in close contact (such as a classmate sitting close by) with chickenpox, then you should inform your renal unit as soon as possible in case your child needs a vaccination called ZIG. If your child develops a rash from chickenpox then get in touch straight away so that we can start treatment early.

Another virus that can cause illness following transplant is called cytomegalovirus (CMV for short). This is a virus which causes a mild flu-like illness usually, but can be a more serious infection for people on immunosuppressant drugs. Both your child and the kidney are tested for CMV before transplant. If your child has never had CMV (i.e.CMV negative) and receives a CMV positive kidney, there is a possibility that he/she will develop CMV. If your child is CMV positive, this is less likely to occur but may still do so. Another virus that can cause concern is EBV which is the virus that can cause glandular fever. In rare cases the virus can cause a condition called PTLD (Post Transplant Lymphoproliferative Disorder) where the immunosuppressants need to be reduced and other treatment required.

6. What about drugs prescribed elsewhere after a transplant?

There are some antibiotics and other medications which can interact with transplant drugs. If drugs are prescribed by other doctors, then please **check** with the renal unit.

7. What if my child has sickness and diarrhoea?

These can interfere with the absorption of drugs into the body. If your child is improving during the day then the drugs can be given at a later time. If your child cannot keep any drugs down all day then please contact the unit for advice. If your child vomits back his/her tablets within an hour of taking them then the drugs should be given again.

8. Benefit changes

Social Security benefits to which you are entitled will change post-transplant. It is best to seek advice from the social worker as the circumstances for each family and child is different.

9. What do we tell the children about where the transplant kidney came from?

This sensitive question will need a sensible answer and is best discussed with team members.

10. Can my child have children in the future after the kidney transplant?

If the transplant is working well and your child enters adulthood with good health and good kidney function then it is possible for them to have children of their own. Contraceptive advice should be sought at the appropriate time. Use of the pill must always be discussed with the nephrologist.

11. If my child has appendicitis post-transplant is there risk to the transplant kidney?

Not usually.

12. Are there precautions regarding skin care?

As the immunosuppressant drugs increase the sensitivity of the skin to the sun's harmful effects, avoidance of over-exposure to the sun and the use of sun block creams and hats is strongly advised. There is an increased risk of skin cancer in post-transplant patients and all suspicious moles or warts should be reported to the doctor.

13. Does my child require antibiotic cover for teeth extraction?

No, unless there is another reason for giving antibiotics such as a heart valve problem.

14. Will my child need to attend clinic forever?

Even when the transplant has been in place for several years, clinic visits are still needed 3-4 monthly to monitor blood pressure and kidney function.

15. When will my child be transferred to the adult transplant unit?

Young people are usually transferred when it is right for them and they have finished their growing or schooling. So it may be any time between 16 and 20 years! We will discuss the transfer with you all well in advance and provide the young person with a **transition pack** from the age of 14 years onwards to prepare him/her for the transfer to an adult unit that is usually closer to home.

useful terms

Antibodies
Proteins in the blood stream which react against foreign substances.

Artery
Blood vessel which carries blood away from the heart to the organs of the body.

Biopsy
Removal of a tiny piece of kidney tissue for special examination under a microscope.

Bladder
The sac which holds urine before it is passed out of the body.

Blood group
The type of blood you have, ie groups A, O, AB, B.

Deceased donor
A kidney donor who has died.

Cannula
Small plastic tube inserted into a blood vessel.

Creatinine
Waste product in the blood stream which is removed by the kidneys. Measuring the level tells us how well the kidneys function.

Cross matching
Test which matches your child's blood against cells from the donor.

Hypertension
High blood pressure.

Immunosuppressant drugs
Drugs given to damp down the body's response to the transplant kidney and prevent rejection. Azathioprine, Tacrolimus, Mycophenylate Mofetil (MMF) and Prednisolone (steroids) are the drugs commonly used.

Intravenous infusion
Fluid given through a cannula (commonly known as a drip).

Living related donor
Kidney donor who is a living relative of the child, usually a parent.

Recipient
Child who receives a kidney transplant.

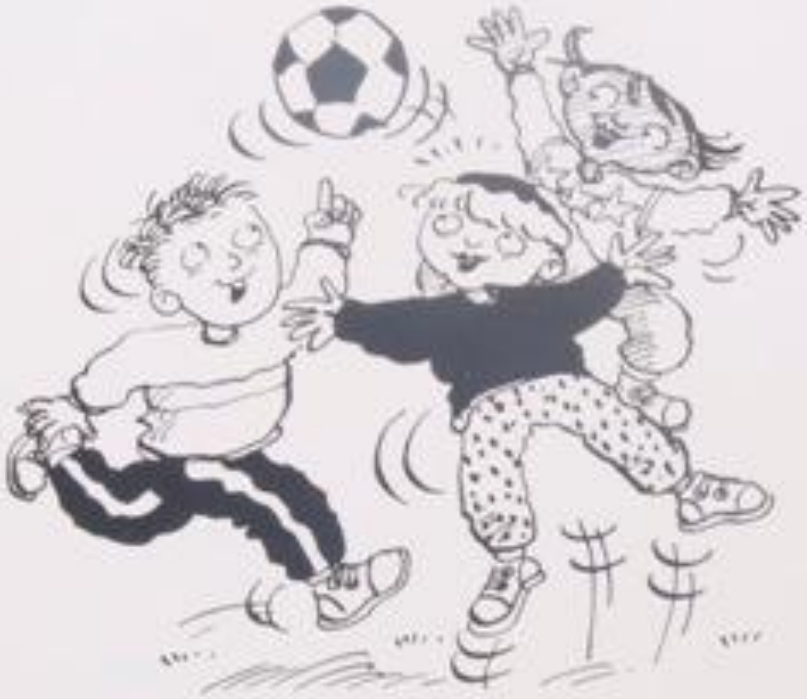
Rejection
Vigorous response of the body's own cells to the kidney transplant. Steriods or occassionally other drugs are used to treat it.

Tissue type
Proteins on the surface of cells which define our individuality.

Ureter
Tube which carries urine from the kidney to the bladder.

Urinary catheter
Tube which drains urine from the bladder.

Vein
Blood vessel which carries blood away from the organs back to the heart.



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