Information For Parents and Carers

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Kidney Transplant

This booklet will explain common issues in paediatric kidney / renal transplantation. It is not possible to include every aspect of transplantation in one booklet as each child’s experiences and care will differ slightly. Please allow yourself time to read this booklet. All issues concerning your child’s care will be discussed with you at length by your renal team – and you are free to ask questions of any member of the team at any stage.

Why Is A Kidney Transplant Necessary?

Kidneys are important for our body as they filter our blood to remove waste products and fluid from our body. Kidneys also produce hormones which help to produce red blood cells and control blood pressure.

When kidneys are affected by disease, they do not work as efficiently as they should. The important functions they carry out must then be replaced by dialysis or a kidney transplant.

Before your child needs a transplant they will be diagnosed with chronic renal failure by the renal team at the Children’s University Hospital.

There are several causes of chronic renal failure (CRF). The speed which it deteriorates differs with each child. Children with CRF will require a renal transplant at some time in the future.

As CRF deteriorates, it is referred to as end stage renal failure (ESRF). At this point, your child’s kidneys are too damaged to carry out their functions and Renal Replacement Therapy (RRT) is required.

There are different types of RRT. These include;

- Peritoneal Dialysis
- Haemodialysis
- Renal Transplant

The choice of replacement therapy for your child will depend on your child’s medical needs and will be decided in consultation with you. The doctors caring for your child will discuss their options on the type of RRT as early as possible to give you time to discuss it together.

This booklet only discusses renal transplantation. There are other booklets available which discuss haemodialysis and peritoneal dialysis. We recommend you read this in stages allowing yourself time to absorb the information. It may also be helpful to show this information to family members or friends so they too can have an understanding of what is involved in transplantation.

What Is A Kidney Transplant?

Kidney transplantation is the treatment of choice for many children with ESRF as it has many advantages. It allows your child a lifestyle free from dialysis and fewer fluid and dietary restrictions. Transplantation is the most effective way of treating kidney failure. However, it does not always correct all the complications of the original kidney problem.
Maintaining the health of your child’s transplanted kidney will require close involvement with you, your child and the renal team.

In ideal circumstances we would hope to provide a kidney transplant before your child needs dialysis. This is known as pre-emptive transplantation.

Pre-emptive transplant avoids the need for dialysis – therefore causing less disruption for your child and none of the potential side effects and risks of dialysis.

Unfortunately, pre-emptive transplants are not possible in some conditions and for many children dialysis is unavoidable for a variable period of time before transplant.

**Kidney Transplant; What is Involved?**

There are a number of stages before and after a kidney transplant.

1. Physical Assessment
2. Preparing You And Your Child
3. Factors That Determine If A Kidney Is Suitable
4. Preparation On The Day Of Transplant
5. Immediate Post Operative Care
6. Potential Complications Of Transplantation
7. Maintaining Your Child’s Health After Transplantation

1. Physical Assessment

The decline in kidney function from CRF to ESRF is usually very slow, it may be over several years. However some children can have an unavoidable sudden decline in kidney function.

Careful monitoring of your child’s blood results and adhering to diet restrictions and supplementation as advised by the renal team may help slow down the progression of renal disease and delay the need for RRT. Some children need blood pressure medication known as anti-hypertensives.

All children approaching ESRF will be prepared for renal transplant. However some children will require dialysis first for a period of time. This will depend on a number of factors:

- Blood pressure control,
- Original diagnosis
- Monitoring of your child for an adequate growth rate.
Often children with kidney problems also have bladder problems. Part of the preparation for transplantation is to assess if your child has an adequately functioning bladder. Some children require surgery on their bladder (months before their transplant) to make sure it can safely tolerate the volume of urine the transplanted kidney will produce.

Some children have to wait for some time i.e. years after transplant for bladder surgery. There are many reasons for this. This will be discussed individually with each family.

Babies who are born with ESRF must be at least 2 years of age AND have grown to a suitable weight (minimum of 10 kilos) AND length / height before they can safely be considered for transplantation. This will be discussed with each individual family.

A number of routine or baseline tests will be carried out to ensure that the team has as much information about your child’s condition as possible.

These include:

a) Blood samples for your child’s tissue type* (this will be explained – page 5), blood group, viruses e.g. EBV, CMV, Hepatitis B and C and HIV.

b) Blood anti-body levels.** (this will be explained – page 6)

c) Chest x-ray.

d) **ECHO cardiogram** (heart scan).

e) Abdominal and kidney ultrasound.

f) Dental check - by your own dentist.

g) All vaccinations must be up to date including

   BCG
   Hepatitis B
   4 in 1 or 6 in 1
   MMR
   Pneumococcal
   Meningitis C

   some booster injections may be necessary.

h) Chicken pox vaccination if your child is not already immune.
2. Preparing You And Your Child

When your child has completed the physical assessment and all results are examined you will meet with the paediatric transplant team. You will have the opportunity to discuss what transplantation will involve for your child.

Preparation is very important for the family. This will be carried out by the Nephrologist (kidney specialist), Nurse Specialist, Play Specialist, Psychologist and other members of the renal team.

Once your child is medically ready to go on the transplant list an appointment will be made for you and your child to meet with the transplant team who will then make the necessary arrangements for placement on the national transplant waiting list.

You will hear two terms used when your team talks about transplantation.

Firstly there are cadaveric donations (deceased donor)– this refers to kidneys that are offered when a person dies and had expressed a wish that in such an event their organs would be donated.

When such a donation is made the kidney is given to the most suitably “matched” recipient. They are “matched” by comparing the tissue typing of both donor and recipient.

Secondly, there are live related donations [LRD] – this refers to a relative, usually a parent, donating their kidney to a child.

The benefits of LRD are;

- Can be planned to fit in with family circumstances
- Child may be transplanted before the need for dialysis. However, for a number of reasons this is not always possible.

The long term success of transplants are better with live related kidneys. However it is not always possible for a parent to donate due to;

Age of the relative
Different blood group
Their blood may react with their child’s blood on testing
They may find that they are not medically fit themselves

LRD has a significant psychological impact on the family unit and we respect that many families for private reasons will not choose this option.

The decision as to which type of transplant your child will receive will be discussed with you by your child’s paediatric renal team. If, as a parent you decide to explore the option of a live related donation, please discuss this with the renal team in Temple Street Children’s University Hospital (TSCUH). If it is medically appropriate and you have a compatible blood group to your child you will be referred to the transplant co-ordinator (Beaumont).
Before your appointment with the surgeon (for cadaveric or live related transplantation), you will meet with your child’s consultant nephrologist who will explain medical information about the transplant and potential risks as well as benefits.

If you think of questions you would like to ask about the transplant, write them down and bring them along on the day.

The play specialist has a very important role in the preparing your child for transplant. A visit to the area where your child will be nursed after the operation can be arranged where possible. Play activities will be individualised to meet your child’s needs. You will also get the opportunity to meet other members of the team including a dietitian, medical social worker, ward nurses and psychologist.

If you are thinking about kidney donation there is a comprehensive book available to download on www.beaumont.ie. We would strongly advise you to read this booklet for more information on donation and issues on LRD transplantation.

3. Factors That Determine If A Kidney Is Suitable

As mentioned above, a donor kidney is deemed to be a “match” to a recipient by comparing the tissue typing of the donor kidney to the recipient. This applies to both cadaveric and live related transplants.

**Tissue Type**

Tissue typing is a test that identifies very specific parts of cells in a blood sample. It specifically looks at the **Human Leukocyte Antigens** (HLA). HLA matching is a complex subject and will not be explained here in detail. In simple terms we produce millions of antibodies which primarily are intended to fight off disease or infection.

Some children may have a rare HLA combination and it is very difficult to find an ideal match. In these cases, a kidney with less HLA in common may have to be considered. It would be **very rare** to receive a cadaveric kidney that had a full or complete match to your child.

*When checking the HLA types of family members an inadvertent side effect of the test is that we sometimes find that family members are not related to each other in the way they thought they were. This is not in any way the purpose of the test we do, simply a side effect of the test which is necessary for donation.*

The details of all patients requiring a kidney transplant in Ireland are kept on a database at Beaumont Hospital. When a donor kidney becomes available the transplant team looks at matching the tissue typing of the donor with the best match to all the recipients’ / on the list.

There are several factors that influence how suitable a kidney is to the recipient.

- A) Blood groups need to be compatible
- B) Appropriate tissue typing
- C) Antibody levels
- D) Length of time on waiting list
When all of these factors are considered and the transplant team decide the kidney is best suited to you they will phone you and ask you to make your way to TSCUH. When you and your child arrive to the ward, several final checks will be made. One essential test is repeated. That is the antibody test; it is often referred to as the “cross match”.

**Antibody Test**

This is quite a complicated laboratory procedure and will not be explained in detail here. In simple terms, it tests your child’s blood against the blood of the donor for any indication of incompatibility.

If the result of the cross match is **positive**, this indicates there is an adverse reaction between the two samples and the transplant **CANNOT** go ahead.

Once your child’s blood has been taken it, can take approximately **four hours** for the result. When the cross match result is **negative** the transplant **may proceed** provided the child is deemed medically fit for surgery on the day.

**Practical Issues When On Call**

A cadaveric kidney may become available at any time and when your child is placed on call for a kidney you will be asked to be available for contact at all times by telephone.

It is very important that if you change your telephone numbers while on the waiting list that you notify the Clinical Nurse Specialist and the Transplant co-ordinator of your new details.

Likewise, when you are on the list for a period of time some people choose to leave the country for a holiday. It is important to let the team know so that you can be temporarily suspended from the list for this period of time.

Your child’s team will work towards maintaining his / her health while on the waiting list as the transplant operation cannot go ahead if they are sick.

**4 Preparation On The Day Of Transplant**

When you get a call from the Beaumont team to say there is the possibility of a suitable kidney, you must make your way to TSCUH. From the time you receive the call from the transplant co-ordinators, **you should not allow your child anything to eat or drink**.

On arrival to TSCUH, blood samples will be taken as already discussed. Children on peritoneal dialysis will have a specimen of dialysis fluid sent to rule out peritoneal infection.

Some children may require dialysis before the transplant.

Where possible, a specimen of urine will also be sent to rule out a urinary infection.

Before the operation, your child will have a chest x-ray taken. This will be reviewed by a member of the anaesthetic team to ensure that they are fit for surgery.
When:

1. Blood results are within safe limits and
2. The "crossmatch" is negative and
3. The child is infection free and deemed fit for theatre by the anaesthetist

The transplant will go ahead

The transplant operation usually takes three or four hours. The operation will be performed in TSCUH by the transplant surgeons from Beaumont Hospital.

The transplanted kidney is placed in a different place to your child's own kidneys. The new kidney is placed at the front of the abdomen (tummy area). Generally, your child's own kidneys are not removed.

In young children, the kidney is surgically sewn onto the main artery going through the abdomen which is called the aorta. In these children, the scar will run down the middle of the abdomen.

In older children, it is attached onto a large internal vein that supplies the leg, usually on the right side. In these children, therefore, the scar will be above the groin area.

The transplant consists of the actual kidney and its own ureter. The ureter is the "tube" that brings urine from the kidney to the bladder.

The transplanted ureter is sewn into the bladder. Sometimes a stent is placed in the transplant ureter during the operation.

A stent is a small plastic tube that can be placed into the transplant ureter to reduce pressure where sutures/stitches have been used. If a stent is used, it is left in place for a few weeks after surgery. The surgeon will then arrange a time to remove it when necessary under a general anaesthetic. If your child was on dialysis before the transplant, the permacath/tenckhoff may be left in place and surgically removed 6-8 weeks after their transplant.

5 Immediate Post Operative Care

When the transplant kidney has been placed, it is important that it receives adequate fluids to make sure it works correctly. This will require a large volume of fluid to be given intravenously (using a drip) in the immediate post operative stage.

Your child will have a urinary catheter in their bladder for a number of days after the transplant to allow accurate measurement of urine produced by their new kidney.

On return from theatre your child will have a number of tubes, one will be a line into a large vein in their neck leading into their heart to help in assessing your child’s fluid levels and it will be used to give fluids, medications and take blood samples.

Your child will also have a tube into an artery in their wrist which will allow accurate measurement of blood pressure as well as blood sampling.
All of the above requires careful monitoring and your child will have “one to one nursing” for the first 24 - 48 hours and longer if necessary.

Together with the pain control team, we aim to give your child adequate pain relief for this initial period – most children are on a morphine infusion for the first 24 hours after their operation.

Due to the amount of monitoring after the transplant and number of catheters and lines in place, younger children go to the paediatric intensive care unit for a few days post transplant for their care. Many younger children are sedated and ventilated (i.e. on a breathing machine) to allow for rest and to reduce their distress.

Older children are transferred back to the ward post-operatively where they will have “one to one nursing” for the first 24 - 48 hours.

Sometimes, due to the amount of fluid your child requires for their kidney to function they may have a rise in their blood pressure or a build up of fluid in the lungs making breathing more difficult. If this happens your child will be carefully monitored and may be transferred to the intensive care unit for a short period, during which time the renal team will discuss changes in treatment with you at regular intervals.

It is not unusual for the kidney not to work straight away. This is often called a ‘Sleeping Kidney’, It may take 2-3 weeks to work fully. Because of this, your child may need dialysis after their transplant. If this happens, the team will speak with you regularly and discuss any changes to your child’s treatment.

It may be necessary to perform a kidney biopsy to accurately diagnose why the kidney is not working. The team will discuss this with you at the time. A biopsy requires a general anaesthetic and a tiny piece of kidney is removed – using a very fine needle.

After a transplant, it is hoped to see a steady decline in your child’s blood creatinine. Creatinine is produced everyday by the body and can only be removed by the kidney. A rise in the level of creatinine in your child’s blood may indicate that the kidney may not be working correctly. Creatinine is used as a indicator as to how well the kidney is working.

Careful monitoring, as described above, will continue for as long as required for your child. It is hoped that after 5 days your child will require less “tubes”, feel in good health and be able to move around freely.

Younger children can take longer to fully recover. Sometimes it is 2 - 3 weeks before they are back to their usual activities and will most likely spend 5-6 weeks as an inpatient.

The length of stay in hospital depends upon each child’s general health and how quickly their new kidney begins to work. Your child will be closely monitored for many factors including creatinine level and medication levels.

When all is satisfactory with your child’s general health and you have received post transplant education your child will be discharged. The average stay in hospital post-transplant for older children is 3 weeks.
Recap!

The information this far relates to how children are assessed for transplant and some of the processes involved in the days around their operation. As indicated at the beginning this is a lengthy document and it is not possible to include all eventualities in this booklet.

Children who need a kidney transplant share the diagnosis of End Stage Renal Failure (ESRF). The causes of kidney failure vary and each condition affects children in many different ways. The renal team will discuss your child’s individual condition with you and if complications arise post operatively the team will explain any alterations to your child’s planned treatment.

The aim of this booklet is to inform and prepare you for your child’s operation. Kidney transplantation is the optimum treatment option for patients in ESRF and when successful does result in a better quality of life for a child. We recognise that a kidney transplant requires a huge commitment by a demanding treatment routine. Ongoing support from the renal team is essential.

As with all operations, there are many potential complications. However, not all patients will suffer all the complications. Most children will have at least one complication. Even when a child has more than one complication they can have a complete recovery with a successful transplant.

The following information aims to highlight some of the most commonly seen complications. **Reading all of this information can be overwhelming and it is important to remember that not all patients suffer all the complications.**

The potential complications will be discussed with you by the team and you will have time to ask questions during clinic visits. This document can be used as a reminder to the discussions that have been had in clinic.
6 Potential Complications Of Transplantation

(1) **Rejection** occurs when the body recognises the transplant kidney as “foreign” and the body’s immune system produces cells that “attack” the transplant. To prevent this happening **immunosuppressant** medications are given.

As more efficient immunosuppressive drugs have been developed, acute kidney rejection is seen less often. However, it is still a possibility.

When rejection occurs there is a rise in creatinine, this is an indication that the new kidney is not working correctly. Rejection can be treated with additional immunosuppressant medications. In some rare cases, the rate of rejection is so severe that the kidney fails and the only option is to remove it.

Most rejection episodes are small and can be reversed. Some kidneys have some permanent damage from a rejection episode but can continue to work.

One sign of rejection is a significant or persistent rise in creatinine. As there are other causes of a rising creatinine it may be necessary to perform a kidney biopsy to confirm the diagnosis.

Sometimes, when rejection happens there may be no signs / symptoms. Important points that can reduce the risk of rejection include:

- Maintaining ideal levels of immunosuppressant medications
- Ensure the medications are taken at most effective times
- Adequate fluid intake at all times
- Be aware of some of the warning signs of rejection
- Regular attendance to the renal clinic

The signs and symptoms of rejection can include the following:

- Flu-like symptoms such as chills, headaches, fatigue, and high temperature
- Pain/redness over the kidney site
- Reduction in urine passed

If your child has any of the above symptoms you must contact the renal team as soon as possible.
As these symptoms are similar to many common infections, the patient will be observed carefully and all necessary investigations performed to diagnose the problem.

If rejection is diagnosed and requires treatment, the team will discuss this with you.

**2) Seizures:** For some children, the combination of the new medication, the large volume of fluids and a change in blood pressure can cause a seizure or fit.

Seizures are treated immediately with medication. Some children may have to take this medication for a longer period. Many children who have a seizure, sleep for a time afterwards and can be sleepy for a day or two. Some children may need to ventilated in the **Paediatric Intensive Care Unit** (PICU) to allow them to rest and minimise their distress due to the seizures. **A seizure does not mean your child has developed epilepsy.**

**3) Infection:** Children taking immunosuppressant medications are more susceptible to infection, both bacterial and viral. The most common viral infections that can affect transplant recipients are **cytomegalovirus** (CMV), **Epstein Barr Virus** (EBV) and the **BK Virus**.

These viruses are present in the general population. When a person comes into contact with these viruses, they may be unwell for a short period of time (often with flu like symptoms) and then recover without using medications.

When a person has had such an infection, they generally develop immunity to the virus and their immune system can defend against the virus the next time they are exposed to it.

Children who are on immunosuppressant medications are often slow to develop immunity and therefore the virus may remain active in their system for longer. In a small number of children these viruses may lead to cells becoming cancerous due to immunosuppression.

It is, therefore important that these children have regular blood tests to monitor the activity level of the virus. It is often necessary to reduce immunosuppression doses slightly, this will help a child’s natural immunity to develop. Some children may require treatment with antiviral medications if they are unwell with these viruses.

**4) Surgical Complications:**

(A) Occasionally urine leaks at the point where the ureter is stitched to the bladder. If this happens the child will return to theatre to have the stitches redone.

(B) During the initial post-operative period there is a risk that a thrombus (clot) will form at the point where blood flows into the kidney. If this happens the child may need to return to theatre for an other operation. If the thrombus (clot) can not be successfully removed the transplanted kidney will be removed.

(C) Children with complicated bladder problems may require additional surgeries some years after their transplant to improve drainage issues.

There are other possible complications which will be discussed with you by your child’s surgeon. Your consultant nephrologist will discuss all of these **potential** complications and more with you at one or more clinic visits.

Again, it is important to remember that they are potential complications and not all patients have complications. All children are monitored carefully after their transplant and if the team have any concerns they will discuss them with you.

**You are not expected to remember all of this information.**
7. Helping Your Child Stay Healthy After Their Kidney Transplant

When your child is ready to be discharged after his/her transplant, follow-up outpatient appointments will be discussed with you before you leave.

At this time, you will be given advice and instructions about your child’s medication and post-operative care together with fluid intake and dietary advice. You will have the chance to talk with the team about any questions you may have.

It is important that your child attends all their follow-up outpatient appointments. During these visits, your child will have several routine blood tests which will monitor their general health and condition of the transplanted kidney.

These blood tests are vital in detecting a problem e.g. infection, rejection or a low/high drug level. **Important** Tacrolimus (Prograf) and Mycophenolate (Cellcept or Myfortic) are two medications your child must take every day.

The blood level of these medications must be carefully monitored. Therefore, on the day of your appointment they must not be taken until after your blood test.

Bring these medications with you and give your child their regular dose immediately after the blood has been taken. This will be explained to you as part of your child’s discharge education.

In addition to blood tests the outpatient follow-up will consist of:

- Adjustments to medications if necessary
- A physical examination
  - The chance to receive further education and support in the care of your child post-transplant and the chance to ask any questions or any concerns you or your child may have.

Your child’s outpatient appointments will be more frequent in the first year after their transplant and will vary according to your child’s progress, creatinine, drug levels and presence of any complications.

Six months after your child’s transplant, we aim to review them every 3-4 weeks. The schedule will be different for all children and it will be tailored to your child’s individual needs. The team will inform you of the clinic schedule for your child.

**Medications Used To Prevent Rejection**

Often, after a child’s transplant, medications that were previously taken can be stopped. Occasionally, if your child was taking blood pressure medication they may continue for a period of time after the transplant.

There are positive and potential unwanted side effects to all medications. Many of the negative side effects occur in only a few children. It is not possible to predict which children will suffer from which side effects. Unwanted side effects are often temporary and when reported to the team can be stopped by changing your child’s medication routine.

For the purpose of this document only the most commonly seen side effects will be discussed.
**Basiliximab (Simulect)**

This medication is used to suppress the immune system and prevents rejection. It is given in two doses. The first is given at the time of transplant and the second four days later.

Some children may develop breathing difficulties and require oxygen after they are given basiliximab. If this happens the second dose may not be given.

**Other anti-rejection medications are:**

**Steroids.**

The intravenous form is called **Methylprednisolone** and the tablet form is called prednisolone.

Steroids suppress the immune system and reduce the production of cells that can lead to rejection. A short course of high dose steroids is given in the immediate after the transplant period and is reduced over a period of time.

Possible side effects of steroids are fluid and salt retention and high blood pressure. The team will monitor this and other medications can be given to reverse this problem.

Steroids can lead to an increase in appetite – this returns to normal when the steroids are reduced.

Some children may have mood changes – increased irritability when on high dose steroids. This also returns to normal when the steroids are reduced.

**Tacrolimus (Prograf)**

This is a very important anti-rejection medication which suppresses the immune system and reduces the production of specific cells that can lead to rejection.

Your child will have to take this medication for as long as the kidney stays healthy.

Tacrolimus will be prescribed either twice or three times a day. It is important that your child takes this medication exactly as advised.

Tacrolimus should be taken on an empty stomach. This means your child cannot eat for half an hour before they takes the medication **AND** they must not eat for half an hour after taking it. Water can be taken during this period.

**Tacrolimus should never be taken with Grapefruit Juice as this interferes with absorption.**

**Tacrolimus interacts with many medications – e.g. antibiotics.** Therefore, it is important that you contact the renal team for advice if your child is given a prescription by your GP or dentist.
Side effects of Tacrolimus can include some of the following:
- Tremor
- Headaches
- Nausea
- Vomiting or diarrhoea.

Less often:
- Raised Blood Pressure / Raised Potassium levels and seizures

In rare cases:
- Diabetes
- Hair Loss

Your child will have a blood test at each visit to measure the level of Tacrolimus in their blood.

If the level of Tacrolimus is too high, it can raise creatinine levels and potentially damage the kidney.

If the level of Tacrolimus is too low it can cause rejection of your child’s kidney. Therefore it is essential that the team monitor the levels carefully. You will be given advice as to how to help ensure accurate levels are recorded.

Diarrhoea may also alter the levels of Tacrolimus in your child’s blood and it is important that if your child is unwell that you contact the renal unit.

Dehydration and vomiting can also raise your creatinine levels and potentially damage the transplanted kidney. **It is important to contact the renal team if your child has diarrhoea or vomiting.**

**Mycophenolate (Cellcept or Myfortic)**

Suppresses the immune system and reduces the production of specific cells that can lead to rejection.

Side effects of Cellcept can include:
- Diarrhoea, vomiting, nausea, abdominal pain.
- Decreased White Blood cell count.

Diarrhoea associated with Cellcept usually improves after 2-3 weeks and can be improved by altering the dose. It is important that the team is made aware if your child has any of the unwanted side effects mentioned above.

Cellcept is taken in two divided does twelve hours apart. It can be taken at the same time as Tacrolimus.

Steroids, tacrolimus and cellcept all suppress the immune system. They all have unique actions and target different cell production.

The medications discussed are the more commonly used and the unwanted side effects are the most commonly seen. This is very general information – you will receive all the necessary information specific to your child prior to your discharge from the hospital.
General Advice Post Transplant

Healthy Eating after Transplant
Once your child’s new kidney is working well, there will no longer be a need for a special renal diet but it is important to have healthy balanced diet.

A healthy diet is important to prevent excessive weight gain. Some of the transplant medications can raise blood sugar levels; Also as a result of renal disease pre-transplant, it is important to look after your child’s diet to prevent high cholesterol and to have a good intake of calcium to maintain healthy bones.

General Advice

- Eat three main meals a day.
- Avoid excessive fried and fatty food.
- Eat plenty of fruit and vegetables.
- Reduce sugary foods and sweetened drinks.
- Avoid adding salt to foods.

School
This can be discussed at your clinic appointments. Depending on your child’s progress they should be able to return to school 8-12 weeks after their transplant. Application for home tuition can be discussed and the hospital school teacher will assist with applications.

Skin, Hair and Dental Care

There is an increased risk of skin cancers in children and adults who take medication to prevent rejection. For this reason, your child’s skin should be kept covered when going out in the sun and a sun screen with a sun protection factor of 50 (SPF 50) applied regularly to all exposed areas.

Your child will receive an appointment at a dermatology sun clinic in the first year after the transplant and every three years after this. This clinic ensures you have all the information you need about the correct creams to apply and how to check for changes in your child’s skin.

Prograf /Steroids can affect the condition of your child’s hair making it weaker.

Good mouth and dental care is essential post transplant. Your child should attend a dentist every six months and regular cleaning is important.

Ensure that you inform the dentist that your child is a transplant patient. Antibiotic cover is not essential for cleaning or general dental care i.e. extractions or fillings. However if your child has any signs of gum infection or a dental abscess antibiotics should be taken e.g. Amoxycillin / Augmentin.

Occasionally for a bad dental abscess a drug called Flagyl may be indicated. This will be necessary but it can interact with Prograf so you should inform the Renal Unit that your child is on this drug and advice will be given regarding the dose, your child will probably need their bloods checked during or after this treatment.
Kidney patients should always avoid the use of non steroidal anti-inflammatory drugs (NSAID's) such as:

- Ibuprofen - Neurofen, Calproten
- Diclofenac - Voltrol, Voltaren
- Mefenamic Acid - Ponstan

Exercise and Sport

After a transplant, we encourage most sporting activities except contact sports such as rugby, kick boxing and hurling. We link closely with the Irish Kidney Association and encourage our patients to take part in the Junior Sports Programme which offers the opportunity of taking part in the National Transplant Games and travel to other sporting events such as:

- British and World Transplant Games
- Tackers Ski Camp

These activities are lots of fun as well as peer support for children and families alike.

The Donor Family.

When children receive a kidney from a deceased donor they and their families often have questions about the donor. All donations are anonymous – the donor details are only known to the transplant co-ordinators and remain confidential.

Donor families will receive a letter from the transplant co-ordinators within a month of their loved ones death, thanking them for consenting to organ donation. The letter does not contain any information which may identify your child.

Many families ask if they can write to the donor family to express their thanks. This can be arranged through the transplant co-ordinators who will pass on your the letters to the donor family.

If you chose to do this we recommend that you allow some time to pass after your child is discharged before you write the letter. It can be written any time after donation as it will always be greatly received by the donor family.

Not all recipients write letters – there is no right or wrong way of saying thank you. Some people send cards.

If you do write a letter, it should not identify you or your child. We ask that you do not date the letter or card as it may be some time before it may be forwarded to the family. Please do not seal the envelope as the transplant co-ordinators will need to check the letter for confidentiality prior to forwarding it to the family.

Some recipient families are unsure of what to write – we can give you some indication of what people have written in the past.

You can describe how your child’s lifestyle was before the transplant and describe the contrast in their quality of life since the transplant. You can include your child’s age, length of time of their illness, whether they are a boy or girl and some family details.
Every family will do it in their own unique way – again there is no right or wrong way. Parents tell us it is the most difficult and emotional letter/card they have had to write and often make several attempts before it feels right for them. When you are ready we can give your letter to the transplant co-ordinator who will make sure it is passed onto the donor family.

Smaller children may not understand or even question where the new kidney comes from but you should prepare yourself for the question should your child ask. You will decide what information you would like your child to have. Your child’s siblings may also question where the kidney comes from - again you should prepare yourself for such situations.

This booklet will explain common issues in paediatric kidney / renal transplantation. It is not possible to include every aspect of transplantation in one booklet as each child’s experiences and care will differ slightly. Please allow yourself time to read this booklet. All issues concerning your child’s care will be discussed with you at length by your renal team – and you are free to ask questions of any member of the team at any stage.
Our campus is smoke free from February 13th 2013

No smoking symbol

Please wash your hands or use hand gel when you are in hospital