Chronic Renal Failure

Information For Parents and Carers

St Michael’s C Ward 01 878 4258

Main Hospital Number 01 878 4200
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Introduction

This booklet will give you and your child some information and advice regarding the management of chronic renal failure in Temple Street Children’s University Hospital. Words you see in bold will be explained in the accompanying Renal Glossary. This condition will need regular follow up by the renal team in the hospital and they will work closely with you to provide the education and support you need.

The renal team consists of a wide range of health professionals. The team includes doctors, nurses, dietitians, medical social worker, psychologist and a play specialist.

When kidney failure happens slowly over a period of time it is referred to as chronic renal failure. This will cause a slow build up of waste products in the blood and other symptoms depending on the extent to which the kidneys have failed. As blood travels around the body, it picks up waste products and unwanted substances such as Urea and Creatinine.

This then travels to the kidneys and is excreted as urine. This booklet will provide you with some information regarding the management of chronic renal failure including dialysis and transplant.

Your child’s kidney function may be stable for many years. The degree of renal function / reduction in function seems to happen when a child’s kidney can no longer cope with the extra work. The kidney may also experience added pressure as your child grows or enters puberty, which may cause deterioration. This is usually very slow and may be picked up in clinic by the renal team.
If your child becomes unwell for any other reason such as vomiting/diarrhoea or a urinary tract infection, it is important to let the renal team know. Early management and treatment may prevent further damage occurring to the kidney during an illness.

**What The Kidneys Do?**

The kidneys are paired organs, situated either side of the backbone just below the ribs. Most people are born with two kidneys; however, one good functioning kidney is enough to meet the body’s demands. Kidneys provide three essential functions:

- They regulate the amount of fluid in the body and produce urine.
- They remove waste products from the blood and pass them out in urine.
- They produce hormones to help control blood pressure, bone growth and the production of red cells.

**Why Do Kidneys Fail?**

There are many reasons your child’s kidneys may fail. Your child may have had an infection, which affected the kidneys, or there may have been a problem from birth (congenital). The kidneys can also become damaged from trauma to the kidney. The kidney specialist (Nephrologist) will discuss the reasons for your child’s condition in further detail with you.
What Treatment Will My Child Require?

In the early stages of chronic renal failure, your child may be treated conservatively using medication and a careful diet. Adherence to diet and medications will play an important role in the management of chronic renal failure. This is also known as pre-dialysis treatment. This stage can last for many years with good adherence to treatment by following your child’s treatment plan carefully.

One aim for the renal team is to ensure that your child continues to grow and develop normally during this stage and this will be monitored at your clinic appointments. The renal dietitian will work closely with you and maintain contact in clinic and by telephone to ensure your child is getting a well balanced diet. Their diet will be tailored to their individual likes and dislikes, while controlling the build up of waste products in the blood.

Chronic renal failure can affect your child’s growth. The main cause for this is poor nutrition, which may be due to reduced appetite or vomiting. It is important not to allow growth to become abnormally slow as this may affect the final height that your child reaches. If growth becomes affected, despite good nutrition, a growth hormone may be prescribed. This is carried out in consultation with your Consultant and other members of the renal team.

Occasionally, children with kidney problems may require supplements or need long-term feeding via a nasogastric or gastrostomy tube. This will be discussed with you in detail if the need arises.
When the kidney function deteriorates and there is less than 10% of normal kidney function, you may hear the term **end stage renal failure** used. This is the stage when it becomes necessary to start **renal replacement therapy** to improve your child’s health.

**Peritoneal dialysis**, **haemodialysis** and kidney transplantation are all types of **renal replacement therapy**. Each of these will be discussed with you in detail by the renal team.

### What Happens In Renal Clinic?

When your child is diagnosed with a kidney problem, they will be seen at regular intervals in the renal outpatient clinic. When your child attends, they will have their weight and height recorded, blood pressure checked and a urine sample reserved.

Blood pressure problems can sometimes occur in children with chronic renal failure. This can be managed with medication and monitoring their fluid intake. You will be advised regarding fluid intake, salt intake and blood pressure control at an individual level in clinic.

It will also be necessary to have blood tests taken to measure the amount of waste products present in the blood stream, such as creatinine and urea. This allows the renal team to assess how well your child’s kidneys are functioning or if there is any need to change some of their medications.
What Blood Levels Do You Monitor?

Most children will feel some level of anxiety when it comes to having a blood test and this is a normal reaction. A special spray may be used before the test, which acts as a local anaesthetic to numb the area and minimise any discomfort. An experienced play specialist works as part of the renal team and can help your child prepare for blood tests and make the experience less distressing.

**Creatinine;** This is a waste product caused by normal breakdown of muscle within the body and is removed by the kidneys. An increasing creatinine indicates a deterioration in kidney function.

**Urea;** Urea is produced when protein in the body is broken down and in impaired kidney function the urea level can become high. If the urea level becomes very high, it can make your child unwell and reduce their appetite. The dietitian will give you advice on how to control your child’s urea levels through high calorie and low protein diet.

**Haemoglobin;** The kidney plays an important role in the production of a hormone called Erythropoietin, which helps to make red blood cells. As your child’s kidney function reduces, this hormone is no longer produced at the required amount. Your child will then need to have injections to help produce red blood cells.

**Calcium, Phosphate and Parathyroid Hormone;** Calcium and phosphate are important for the growth of strong healthy bones. If the kidneys are unable to excrete phosphate, the level will rise. This will increase the production of a hormone
called parathyroid hormone (PTH). This hormone can cause damage to the bones, the bone marrow and the lining of the blood vessels, which can lead to problems in the long term. The kidneys also activate vitamin D, which we get through sunlight and diet. Vitamin D helps us to absorb calcium from food and strengthen our bones.

The phosphate level is controlled by phosphate restriction in the diet and medications to assist in the excretion of phosphate. These medications are called phosphate binders and must be taken with food to be effective. Vitamin D medication is given to raise the calcium levels and prevent PTH causing bone damage. This is a fine balancing act which may result in many changes to medications depending on the blood results.

**What Investigations Are Needed?**

Your child may need to have more specialised investigations to give the renal team more information about the function of the kidney. These may include:

**Ultrasound;** This is a test carried out in the x-ray department and will provide information on the size and health of your child’s kidneys.

**Bone X-Ray;** This is usually an x-ray of the wrist bones to observe for any signs of rickets which can be associated with renal failure.

**Renal Scans;** These can include micturating cystogram, DMSA scan and MAG 3 scan. These scans provide more information on the function of your child’s kidneys and how well the kidneys drain into the ureters and bladder.
Kidney Biopsy: This may be carried out to help your Renal Consultant discover the cause of your child’s kidney disease. It will provide more information on the condition of the kidney. A biopsy is carried out in theatre where your child is given a general anaesthetic. If a biopsy is necessary, your child’s doctor will discuss it with you.

It is important to know that your child can get by perfectly well with 50% function of one kidney, but if kidney function reduces to 20% it will start to affect your child’s health. If this happens you will be asked to attend clinic more regularly. It is very important that your child attends clinic appointments regularly and follows all advice carefully.

Renal Replacement Options

Transplantation
We have developed a separate booklet explaining what you and your child need to know as preparation for a kidney transplant. Where possible, the renal team will plan for an early or pre-emptive transplant for your child. This means that as your child’s kidney begins to deteriorate, your child will be prepared for transplant and if possible, will receive one before the time your child requires dialysis. This is not always possible.

Peritoneal Dialysis
Peritoneal dialysis is a procedure that cleans and filters your child’s blood. This type of dialysis uses the lining of the abdomen (Peritoneum) to act like a filter. A tube, which is placed in your child’s tummy, will exchange fluid in and out of the body. This is carried out at home overnight, meaning your child can still attend school during the day. More information on this will be available in the booklet on Peritoneal Dialysis.
Haemodialysis
Haemodialysis is a procedure that cleans and filters your child’s blood. With this type of dialysis your child has a line which removes blood out into a machine where it is filtered and cleaned and then returned to their body. With haemodialysis, your child comes to the hospital three times a week for this treatment, which can generally be three to four hours long. More information is available in the booklet on haemodialysis.

Before any new treatment takes place, the renal team will discuss it with you and you can ask questions, which are most welcome.

How Will This Effect Our Family Life?

As with any illness, family routine will be disrupted at times. Your child will have to attend hospital for clinic appointments and may have other planned appointments and investigations outside of renal clinic dates. In addition, your child may have to eat a different diet than the rest of the family, which can result in cooking various meals. Restricting snacks and fluids can be difficult but can be negotiated in consultation with the renal dietitian and medical team.

The outlook for a child with chronic renal failure who requires dialysis and transplant is very good. Dialysis allows a child to stay at home with the family, play with friends and attend school. They can still participate in social activities and exercise is encouraged.

After transplant, your child will have improved energy levels and can eat a normal diet. Kidney transplants are very successful, with kidneys lasting many years with immunosuppressant medications.
If you would like any further information, please do not hesitate to contact a member of the renal team at Temple Street Children’s University Hospital. The renal social worker and psychologist will see all families and children diagnosed with chronic renal failure to offer support on many aspects of this diagnosis including how to explain investigations and treatment to your child as well as offering financial advice.

To discuss any aspects of care or issues raised in this booklet, please contact a member of the renal team on the numbers provided below.

01 878 4756 or 01 878 4758

For additional information on renal failure and a comprehensive support network, you can also access:

Irish Kidney Association
Head Office
Donor House,
Block 43A,
Park West,
Dublin 12.
Telephone: 01-620 5306
Fax: 01- 620 5366
info@ika.ie www.ika.
Please remember to wash your hands or use hand gel when visiting the Hospital

Our campus is smoke free from February 13th 2013