

BEAUMONT HOSPITAL

www.beaumontkidneycentre.ie



KIDNEY DISEASE

A Guide for Patients

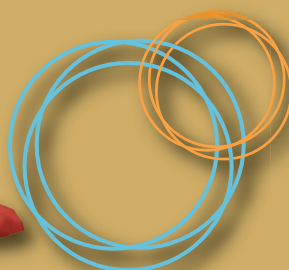
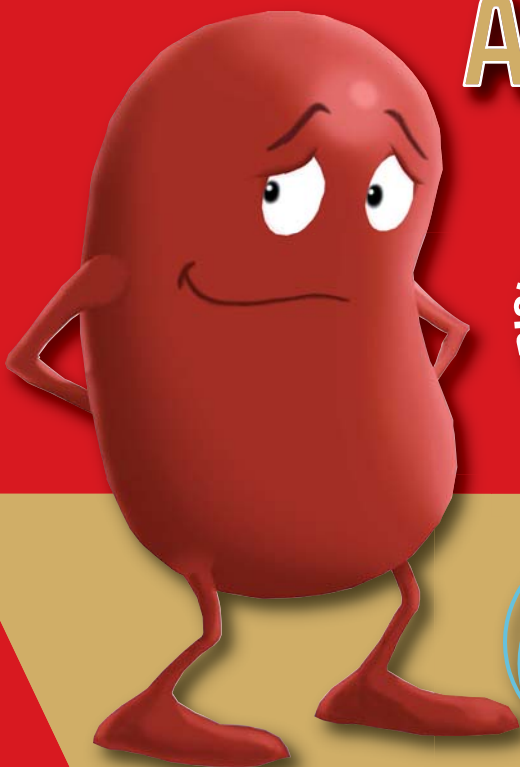
BOOK 1

Petrina Donnelly, CNM

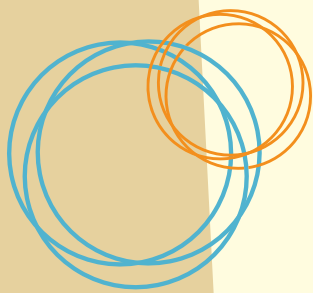
Helen Dunne, CNM

Prof. Peter J. Conlon, FRCPI

3rd Edition



Beaumont
**TRANSPLANT
FOUNDATION**



Beaumont TRANSPLANT FOUNDATION

Beaumont Hospital
PO Box 1297
Beaumont Road
Dublin 9

The Beaumont Transplant Foundation was founded in 1988 with the purpose of providing patient care education and research in the field of kidney transplantation in Ireland. Since that time, the Beaumont Transplant Foundation has allowed many new developments to take place and has assisted, in several education and research programmes, in the area of kidney transplantation. These programmes have been made possible through hard work and great support from individuals, companies and sporting organisations throughout Ireland. This support and generosity has facilitated many groundbreaking programmes and enabled the Transplant Unit, at Beaumont, to become a world leader in its field.

Since 1992, the Transplant Unit has been performing simultaneous kidney and pancreatic transplants on diabetic patients. At present, the Beaumont Transplant Unit is the only facility in the 32 counties that can perform this surgery

concurrently. The benefits of this surgery are inestimable. As a centre for excellence, in the field of transplantation, the Beaumont Transplant Unit has also developed a 'living donor' programme.

In 2009, the Beaumont Transplant Foundation celebrated 45 years of kidney transplantation. Over the last 45 years, 3,700 people in Ireland have received the 'gift of life' through kidney transplantation, with patient outcomes improving consistently.

The Beaumont Transplant Foundation will continue to organise fund-raising events, on an ongoing basis, in order to develop programmes to provide patient care education and research programmes. If you or your family or friends are interested in participating, in any of these events, we would love to hear from you, and would appreciate your support, no matter how big or small. Whether you would like to become a fundraiser or a sponsor, your efforts are warmly appreciated.



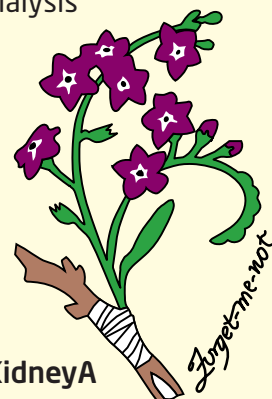
IRISH KIDNEY ASSOCIATION (IKA)

The Irish Kidney Association (IKA) is a national voluntary organisation of patients, family carers and supporters which offers support for all patients with end stage kidney disease. Throughout its 25 local branches, patients can meet other kidney patients and share experiences, problems and, most importantly, solutions.

On a national and local level the IKA organises 'World Kidney Day' functions, around the third Thursday in March, to raise awareness of kidney disease in Ireland. The Association is better known for its national organ donor awareness campaigns the biggest of which takes place in the first week of April each year.

The IKA provides holidays, every year, for kidney patients who are either receiving dialysis treatment or are transplanted. It also has a Support Centre, in the grounds of Beaumont Hospital, which offers on-campus accommodation for kidney patients and their families attending any Dublin hospital and short-term accommodation for the families of seriously ill patients from outside the Dublin area.

IRISH KIDNEY ASSOCIATION, Donor House, Block 43A, Parkwest,
Dublin 12. **Ph:** 01-6205306. **Lo-Call:** 1890-543639 (1890-KIDNEY).
Email: info@ika.ie. **Web:** www.ika.ie.



www.facebook.com/IrishKidneyAssociation



www.twitter.com/IrishKidneyA

PREFACE

In 1983, Dr Michael Carmody compiled the first book of *Living with Kidney Failure*. For more than 20 years, this book was used as the major patient education booklet for patients experiencing kidney disease. During the last 20 years, the technology concerning the treatment of kidney disease has changed radically. As a result we have produced this series of books to assist patients and their families when diagnosed with kidney disease.

This is the third edition of **BOOK 1** in a series of five books, aimed at helping patients with kidney disease learn more about their illness. Book 1 deals with the functions of the kidney, types of kidney diseases, diagnostic tests and medicines used to treat kidney conditions.



BOOK 2 deals with Haemodialysis and Peritoneal Dialysis. **BOOK 3** covers Kidney Transplantation in more depth, whilst **BOOK 4** addresses the area of the 'living donor' programme. And finally, **BOOK 5** is aimed at helping patients with kidney disease learn more about their illness and is specifically written for people who have been informed that they have impaired (or reduced) kidney function and are classified as having Chronic Kidney Disease (CKD).

Please use these books as a guide and reference tool but, any worries or issues you have should be discussed with your medical team. The text includes contributions from many members of the Beaumont Hospital Renal Unit team and has been supported by the Beaumont Transplant Foundation together with the Irish Kidney Association.

We do hope you find it helpful.

Petrina Donnelly CNM
Helen Dunne CNM
Prof. Peter J Conlon FRCPI

January 2014



CONTENTS



3

CHAPTER 1

The Urinary System

8

CHAPTER 2

What is Chronic Kidney Disease?
Causes of Chronic Kidney Disease
Symptoms of Chronic Kidney Disease

18

CHAPTER 3

Diagnostic Testing for Kidney Disease

26

CHAPTER 4

Dietary Advice for Kidney Patients

30

CHAPTER 5

Medications

36

CHAPTER 6

Infection and Vaccination

41

CHAPTER 7

Practical and Social Support

46

CHAPTER 8

Reproductive Matters

48

CHAPTER 9

Your Kidney Healthcare Team

53

CHAPTER 10

Staying Healthy

57

APPENDIX

IKA Renal Support Centre
Glossary
Contact Numbers
Useful Information Websites
Kidney Dialysis Centres
Contributors

The information contained within this book is correct at time of going to press. This book essentially pertains to the practices at Beaumont Hospital. Other Kidney Units may use different practices. This book should be used as a guide and reference tool only.

©This book has been produced by the renal teams at Beaumont Hospital and, save where otherwise specified, the content of all pages are copyright to them. No matter may be reproduced or stored in any way without the written consent of the Editors.

The books have been printed and distributed by the Irish Kidney Association. Further copies are available from IKA, Donor House, Parkwest, Dublin 12. Ph: 01-6205306.

CHAPTER 1

THE URINARY SYSTEM

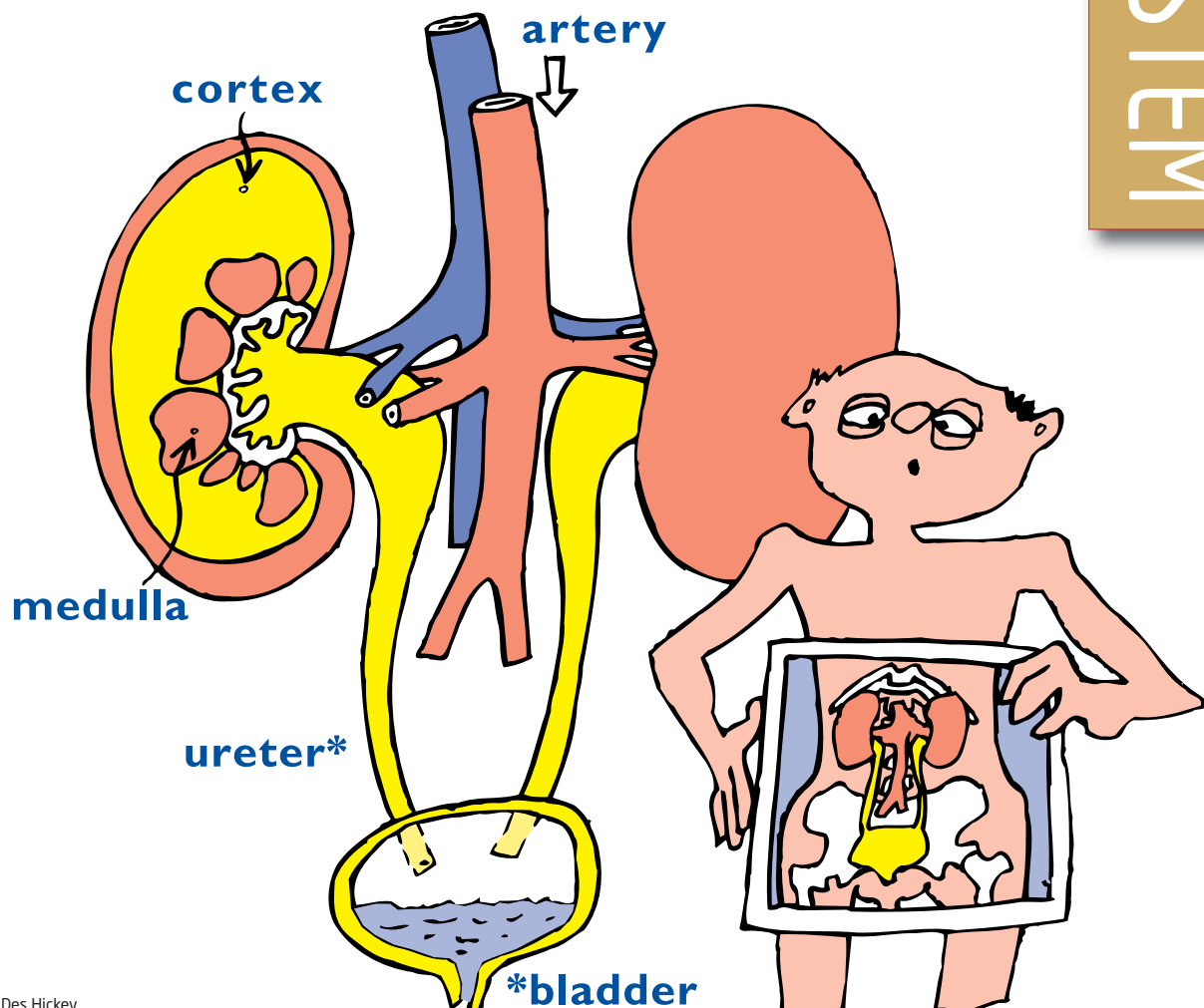
The urinary system is one of the body's systems which helps us to dispose of the waste products naturally produced within the body. The main structures, in this system are:

Two kidneys - which lie behind the other major organs in the lower back area. They are bean-shaped organs and measure about 11cm long, 6cm wide and 3cm deep. They have 5 main functions, which will be discussed at a later stage.

Two ureters - (tube-like features) which run from the kidneys to the bladder carrying urine.

One bladder - which collects urine from the kidneys, via the ureters, and stores it temporarily.

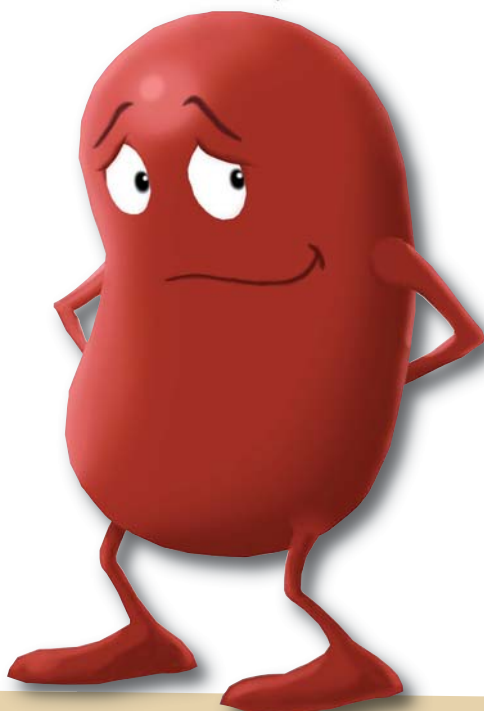
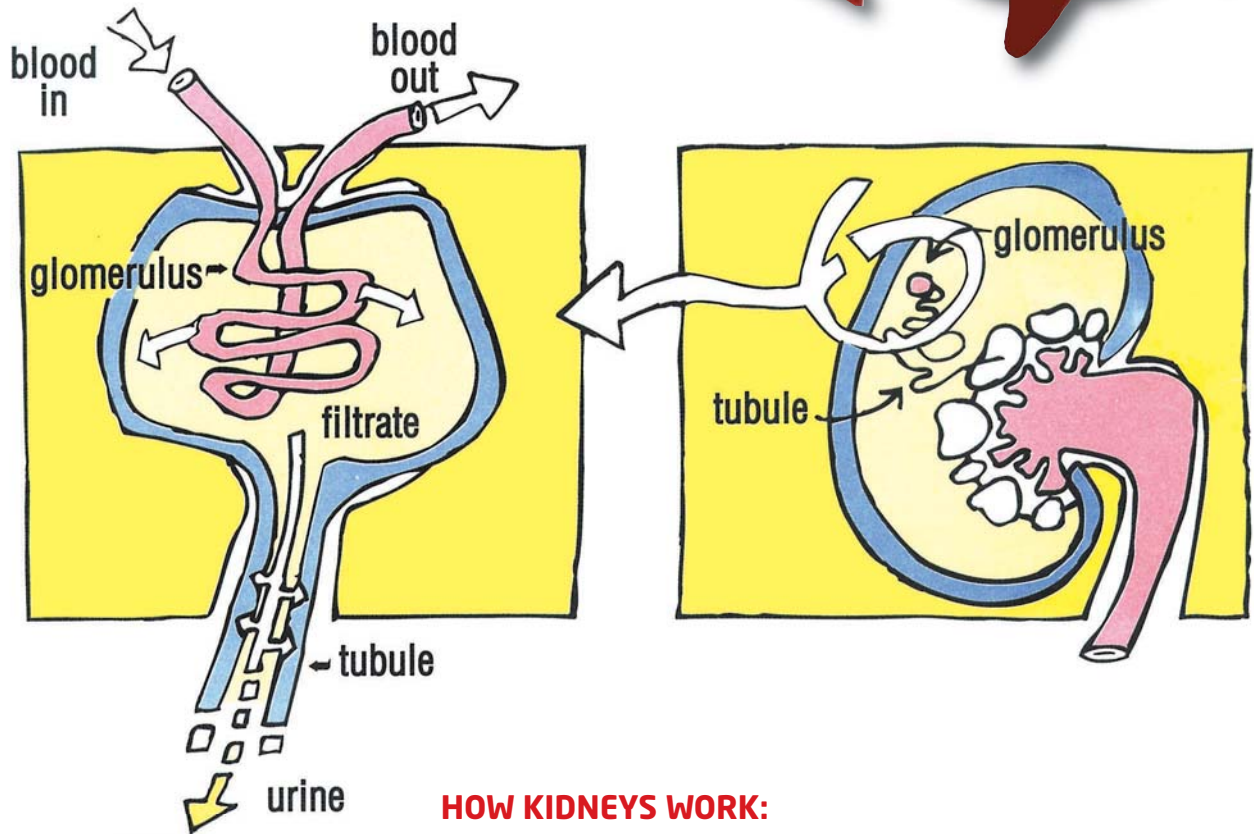
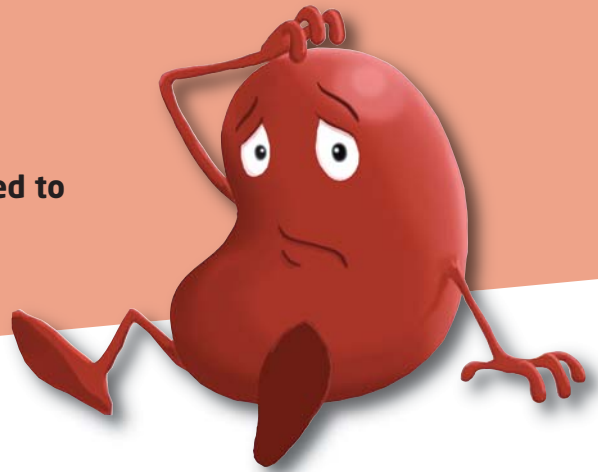
One urethra - through which the urine is excreted out of the body, allowing the bladder to empty and dispose of the waste.



WHAT THE KIDNEYS DO:

The kidneys...

- Filter and remove the waste products of the body.
- Remove excess water from the body.
- Help in the production of red blood cells, which are used to carry oxygen around the body.
- Help maintain healthy bones.
- Help regulate blood pressure in the body.



HOW KIDNEYS WORK:

As blood flows through the body it picks up waste and carries this to the kidneys using the kidney arteries. The waste in your blood comes from the normal breakdown of active tissues and from the food you eat. Your body uses food for energy and self-repair. After the body has taken what it needs, from the food, the waste is sent to the blood. The kidneys filter out the waste products and excess fluids from the body and dispose of them in the form of urine, via the bladder. The clean blood flows back to the other parts of the body. If your kidneys did not remove this waste, it would build up in the blood and cause damage to your body.

The actual filtering occurs in tiny units inside your kidneys called nephrons. Each kidney contains about a million nephrons. In the nephron, a glomerulus (which is a tiny blood vessel or capillary) intertwines with a urine collecting tube called tubules. A complicated chemical exchange takes place, as waste materials and water in your blood enter your urinary system.

Kidney Disease

– A Guide for Patients

SOME EXAMPLES OF WASTE PRODUCTS INCLUDE:

Urea – Blood carries protein from your diet to the cells to fight disease and repair muscle. Whatever protein is not used is put back into the bloodstream in the form of urea for excretion. Too much urea, in the blood, is known as uraemia.

Potassium – A mineral absorbed into the bloodstream from many fruits and vegetables such as oranges, bananas and potatoes. Potassium regulates the heart rate. Healthy kidneys remove excess potassium, from the blood stream, as a waste product.

Creatinine – A waste product in the blood created by the breakdown of muscle cells during activity. The levels vary according to the size of the individual, i.e. the muscle mass of the person.

Sodium – A chemical absorbed in the blood stream from food containing salts. Excess sodium in the blood may cause a rise in blood pressure as it plays a vital role in regulating the amount of fluid in the blood.

Chloride – Like sodium, this chemical helps maintain a balance of fluid in the body. It is also absorbed from salted foods and is absorbed in the bloodstream in the bowel.

In addition to removing waste, the kidneys have other important functions. These are carried out with the help of three hormones, which are released in the kidneys.

Erythropoietin (eh-rith-ro-poy-eh-tin) or Epo is a hormone that is secreted by your kidneys and stimulates the bone marrow to produce red blood cells, which carry oxygen in the blood, to the cells in the body.

Renin (ren-in) is a hormone that the kidneys secrete to help regulate the blood pressure through a chemical process within the blood stream.

Calcitriol (kal-suh-try-ul) is the active form of Vitamin D that the kidneys

secrete to help maintain healthy bones by maintaining a chemical balance between calcium and phosphate in the blood.

HOW DOES KIDNEY DISEASE AFFECT YOUR BODY?

Kidney disease can affect you in a number of different ways. These include :

- Proteinuria (protein in the urine)
- Haematuria (blood in the urine)
- Hypertension (high blood pressure)
- Elevated Serum Creatinine (kidney disease)
- Kidney Stones
- Recurrent Urine Infections

Proteinuria

Proteinuria or protein in the urine is frequently the earliest symptom of kidney disease. You will have read, in the previous section, how the kidney works and that the kidney has about a million filters. When the kidney is healthy it allows very little protein into the urine. If these filters become leaky, small amounts of protein will leak into the urine. This is frequently an early sign of kidney trouble long before the kidney function itself begins to deteriorate.

Doctors frequently test patient's urine for the presence of blood or protein, to try to detect kidney disease early. There are many causes of protein in the urine, including diabetes and glomerulonephritis. Whilst your doctor will conduct a number of special blood tests, to try to determine the underlying cause, it may be necessary to undergo a kidney biopsy (see page 26), to establish the exact cause of the protein.

Patients who have very large amounts of protein in the urine, (greater than 3 grams), are described as having nephrotic syndrome. Patients with nephrotic syndrome frequently have swollen legs.

"Proteinuria or protein in the urine is frequently the earliest symptom of kidney disease."

Haematuria

Blood in the urine (haematuria) can either be present in amounts that you can see (macroscopic) or in amounts that you cannot see (microscopic) in which it is only detected with urine testing. Blood in the urine may not appear red but more like strong tea coloured.

Blood in the urine is frequently an alarming symptom and it should never be ignored. However, it only takes a few drops of blood for the urine to turn red. There are a large number of potential causes of blood in the urine including: urine infection, kidney stones, kidney or bladder tumours and inflammation in the kidney called glomerulonephritis (GN).

If you have haematuria, the first thing your doctor will do is to make sure you do not have a urine infection or bladder or kidney tumour. To do this, you will usually need to have a number of scans of the kidney and may well need a cystoscopy. A cystoscopy is a test in which a camera with a light is inserted into the bladder. If these tests are normal your doctor will then focus on determining if the blood is coming from kidney inflammation or glomerulonephritis. This may require further specific blood and urine tests or a kidney biopsy (see page 26).

High Blood Pressure

High blood pressure (hypertension) may arise due to, or as a result of, kidney disease. It is important, however, to realise that the vast majority of people, with high blood pressure, have entirely normal kidney function. If you have high blood pressure, it is very important to treat it as it will help preserve your kidney function and reduce the risk of developing a stroke or heart attack.

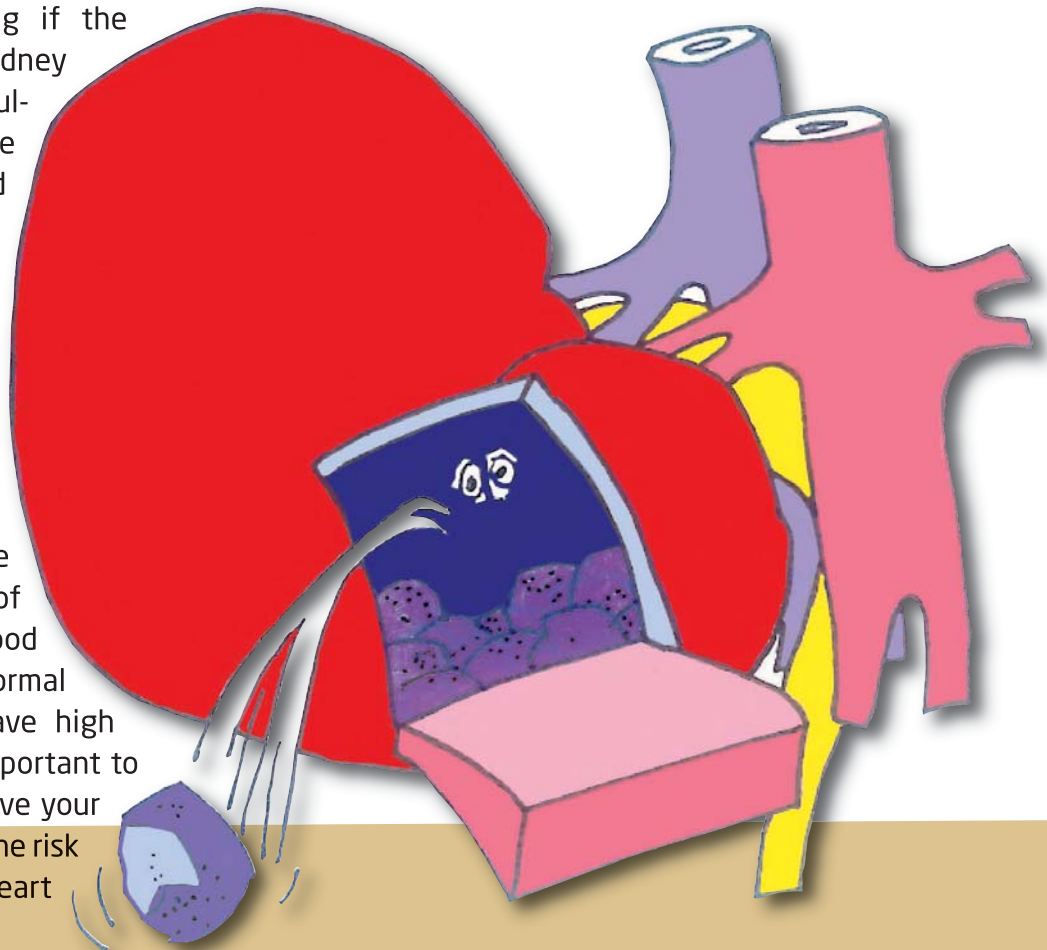
"Blood in the urine is frequently an alarming symptom and it should never be ignored."

Elevated Serum Creatinine

The serum creatinine is a blood test that is used to monitor kidney function. The serum creatinine may be elevated as an early sign of kidney disease long before there are any symptoms evident of kidney disease (see Chapter 2). Blood tests, identifying elevated serum creatinine, are main undertaken, as a routine, during an annual physical medical examination. If serum creatinine is elevated, it may be as a result of any of the kidney diseases discussed below.

Kidney Stones

Kidney stones occur when a tiny fragment of crystal develops within the kidney or the tube coming from the kidney, called the ureter. A kidney stone mainly produces very severe colicky pain. The pain of a kidney stone is described as being more severe than that of labour pains. The treatment of a kidney stone will consist of pain medication initially mainly in the form of an injection.



Kidney Disease

– A Guide for Patients

Subsequently, the doctor/urologist may attempt to extract the stone. This may occur by way of a number of methods, depending on the size and position of the kidney stone. The urologist may pass a scope into the bladder and try to grasp the stone. They may also try to bypass the stone temporarily with a stent, or may try to dissolve the stone with a machine called a Lithotripsy. Occasionally, the urologist may be required to perform an open operation, on the kidney, in order to surgically remove the stone.

Once the stones are removed, the team will attempt to determine their underlying cause. Conditions associated with recurrent kidney stones include:

- Not drinking enough water. If you have kidney stones, it is necessary to drink 3 litres of water a day.
- High levels of calcium in the urine (hypercalciuria). This condition, in which some people pass too much calcium into the urine, can occur for unknown reasons.
- High levels of calcium in the blood (hypercalcemia). This may occur as a result of a gland in the neck called the parathyroid gland becoming overactive. If this is the case you may need to undergo a small operation to remove part of the gland. It may also occur as a result of consuming too much calcium in the diet.

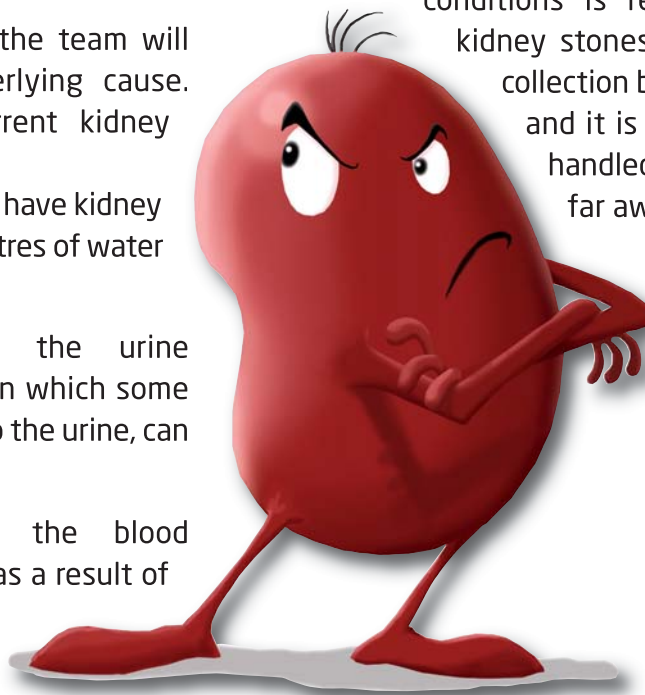
- High urinary oxalate (oxalosis). Oxalate is a constituent of certain foods. If you are diagnosed as having too much oxalate your doctor may prescribe a diet, high in calcium, as this helps to prevent kidney stones in this situation.

"Recurrent urine infections are a common kidney complaint, particularly amongst young women."

- Cystinosis. This is an uncommon cause of kidney stones and is inherited (runs in families). This occurs as a result of the body being unable to handle the amino acid cysteine. The treatment recommended for this condition is to consume large amounts of water. In addition, medications are sometimes prescribed to help reduce the frequency of kidney stone formation.

The investigation of patients with kidney stones will consist of a number of 24 hour urine collections and blood tests to determine which of the above conditions is responsible for the kidney stones. One of the urine collection bottles contains acid and it is important that it is handled with care and kept far away from children.

(See pg 19 for instructions on 24 hour urine collections).



"If you have kidney stones it is necessary to drink 3 litres of water a day."

Recurrent Urine Infections

Recurrent urine infections are a common kidney complaint, particularly amongst young women. The vast majority of patients, with recurrent urinary infection, do not have any underlying structural kidney disease. It is important, however, to eliminate kidney disease by way of performing kidney x-rays. Sometimes long-term (6 months) prophylactic antibiotics are used to eliminate any underlying infection.

CHAPTER 2

WHAT IS KIDNEY DISEASE?

Chronic kidney disease (CKD) is a condition in which the kidneys cannot perform their normal functions. Your kidneys lose the majority of their filtering ability and, as a result, fluid and waste accumulates in your body.

When CKD happens suddenly, it is known as **ACUTE KIDNEY DISEASE** (AKD). The most common causes of acute damage to the kidneys are:

- Decreased blood flow to the kidney: this may occur when there is extremely low blood pressure caused by trauma, complicated surgery, septic shock, haemorrhage, burns, associated dehydration or other severe or complicated illnesses.
- Over-exposure to metals, solvents, x-ray dye, certain antibiotics and other medications or substances.
- Acute Tubular Necrosis (ATN) may occur when the tissues are not getting enough oxygen.

Short-term treatment may be needed for acute kidney disease, but the kidneys usually recover on their own. However, if the cause of the acute kidney disease persists, there can be permanent damage to the kidney, which would lead to CKD.

CHRONIC KIDNEY DISEASE (CKD) usually develops slowly, with few signs or symptoms in the early stages. You may still be passing normal amounts of urine, but it will be poor quality, and waste products, which should normally be filtered out, will remain in the body. Many people, with CKD, do not realise they have a problem until their kidney function has decreased to less than 25 percent of normal (CKD4). This damage usually occurs slowly, and is not reversible.

The rate of deterioration of kidney function is variable, ranging from more than ten years to only a few months.

Eventually, the kidneys can only function at less than 10 percent of normal capacity. The kidneys have almost stopped working at this stage and treatment, in the form of dialysis or a kidney transplant is required to take over the work of the kidneys and maintain life.

This is commonly known as **END STAGE KIDNEY DISEASE** (ESKD). In other words, kidney damage is irreversible and cannot be controlled by conservative management alone. When kidneys reach 'end-stage', they never recover.

PROGRESSION OF CHRONIC KIDNEY DISEASE

Once somebody has some degree of kidney disease it frequently progresses over time. The rate of progression can vary. The stages of CKD can be thought of in terms ranging from 1 to 5.

In CKD stage 1, the patient has normal filtering function as measured by the Glomerular Filtration Rate (GFR) of about 120 mls/min. Other levels of CKD are outlined below:

CKD 1	GFR greater than 90mls/min
CKD 2	GFR 60 to 89
CKD 3	GFR 30 to 59
CKD 4	GFR 15 to 29
CKD 5	GFR less than 15mls/min

Most patients who are diagnosed as having CKD 1, 2, or 3 have only mild kidney disease and do not progress to ESKD. The GFR can be calculated by doing a 24 hour urine collection. Once the GFR is below 70, it frequently continues to decline. If the GFR declines by one ml per year, it will take 80 years to progress from CKD Level 1 to CKD Level 5, requiring dialysis or a kidney transplant. However, if GFR declines by 10mls per year it will only take 8 years to go from CKD Level 1 to CKD Level 5.

Please refer to Book 5 for more information.

CAUSES OF KIDNEY DISEASE

There are hundreds of different diseases that can cause chronic kidney disease. Commonly, the condition is due to one of the following:

DIABETES MELLITUS

Diabetes is a disease in which a patient cannot control the amount of glucose in their blood stream. It is caused either by an inability to produce the substance called INSULIN, which controls glucose in the body (Type 1 Diabetes), or, if the body is unable to respond to the insulin that is produced (Type 2 Diabetes). Whether diabetes is treated by insulin, tablets or diet, it can cause kidney disease.

Apart from raised levels of blood sugar, an important feature, of this disease, is the damage that occurs to small blood vessels. The kidneys contain many small blood vessels and, when damaged by high blood sugar levels in the blood, they are replaced with scar tissue and become blocked. Diabetes can also damage the nerves in many parts of the body. When the bladder is affected, it is more difficult to pass urine, resulting in a build-up in pressure on the kidneys, causing further damage.

The urine of people with diabetes has a high sugar content, which encourages the growth of bacteria and, as a result, kidney infections may occur. Poor sugar control combined with high blood pressure can increase your risk of making kidney disease worse.

HIGH BLOOD PRESSURE

Hypertension means high blood pressure.

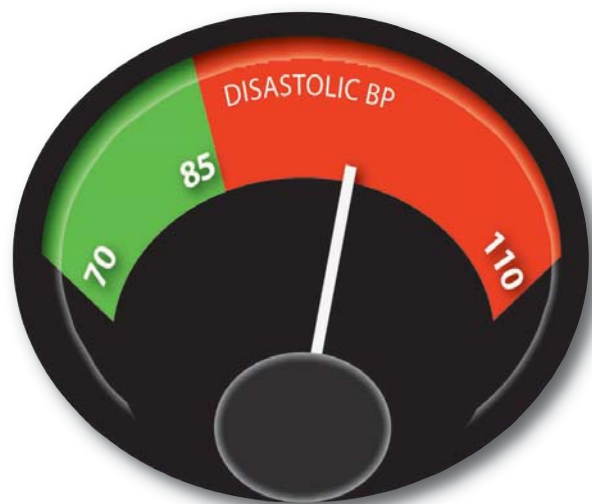
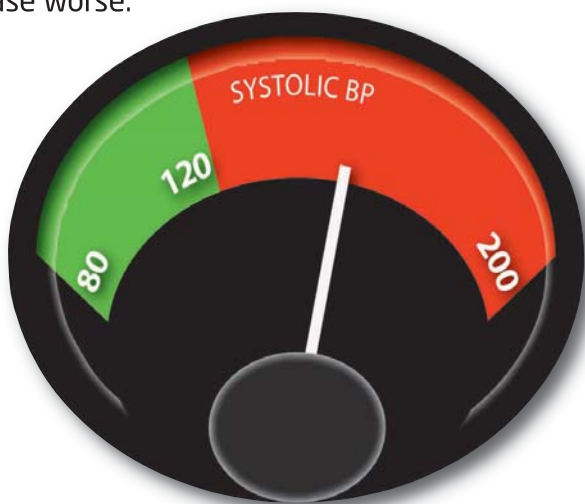
SYSTOLIC blood pressure is consistently over 140 (systolic is the “top” number of your blood pressure measurement, which represents the pressure generated when the heart beats).

DIASTOLIC blood pressure is consistently over 90. Diastolic is the “bottom” number of your blood pressure measurements, which represents the pressure in the vessels when the heart is at rest. Either or both of these numbers may be too high. Severe high blood pressure can, on its own, cause kidney disease. High blood pressure can make other causes of kidney disease worse.

In any person with high blood pressure, blood vessels (especially small blood vessels) become damaged. Roughly speaking, the higher and the longer blood pressure has been raised, the more blood vessel damage is likely to have occurred.

To control high blood pressure, many patients need medications – known as anti-hypertensives. A lot can be done to control blood pressure including changes in lifestyle, weight loss, exercise, and avoiding salt in the diet.

High blood pressure will commonly require medication to keep blood pressure within the normal range.





NEPHRITIS

The term nephritis covers a group of conditions in which there is long-term inflammation of the kidneys ('neph-' means kidney, and '-itis' means inflammation). Sometimes the condition is described more specifically as glomerulonephritis or GN ('glomerulo-' refers to the glomerulus, which is part of the kidney's filtration unit).

When a glomerulus is damaged, substances not normally filtered out of the blood stream, such as proteins, red blood cells and white blood cells, can pass through the glomerulus and enter the fluid that becomes urine. Progressive damage to the glomeruli can cause urine production to fall and waste products to build-up in the blood, leading to kidney disease. There are many types of glomerulonephritis. These may be grouped as primary and secondary.

In primary GN, only the kidneys are affected. In secondary GN, the kidneys are damaged as part of a more generalised disease that can affect other parts of the body. The exact diagnosis can usually only be diagnosed for certain by a kidney biopsy.

Types of GN include:

FSGS - is scarring within the kidneys that can only be seen clearly under the microscope. Therefore, it is normally only diagnosed after a biopsy of the kidney. The name FSGS comes about in the following way:

- F - FOCAL** means that some glomeruli are affected but others may not be.
- S - SEGMENTAL** means affecting only a segment of each glomerulus involved.
- G - GLOMERULO** of the glomeruli.
- S - SCLEROSIS** meaning scarring.

It seems that the general cause of FSGS is immunological. That is, the antibodies and white blood cells that usually fight off infection cause damage to the body by mistake. This condition commonly results in severe swelling of the legs and high blood pressure. The condition may reoccur after kidney transplantation and cause the failure of a kidney transplant. A number of drug treatments are used to try to stop the damage to the kidney that the condition causes. These drugs include steroids, Cyclosporin, Cyclophosphamide and CellCept.

Kidney Disease

– A Guide for Patients

IgA NEPHROPATHY

This is the commonest form of glomerulonephritis in the developed countries of the world. IgA is short for Immunoglobulin A, an antibody which usually helps the body to fight infections and toxins encountered in the gut and lungs. In IgA nephropathy, IgA is deposited in the glomerulus, where they cause inflammation and scarring. In one third of cases, it goes on to cause progressive severe damage to the kidneys. IgA nephropathy tends to be slowly progressive, and so the process of the kidney disease can take 10 to 30 years.

MULTISYSTEM DISEASES AFFECTING THE KIDNEY

The kidney may be affected in many ways by diseases which are not directly associated with kidney function. This is mainly because the kidneys have a rich blood supply, and come into close contact with all elements of the blood.

SLE (Systemic Lupus Erythematosus)

This is a chronic auto-immune inflammatory disease which affects joints, blood vessels, skin, the nervous system and the kidneys. Inflammation of the glomeruli, within the kidneys, may result in protein and blood loss in the urine and high blood pressure. Kidney problems often occurs within three years of diagnosis of SLE.

AMYLOIDOSIS

Amyloidosis is the term given to a group of chronic disorders characterised by the presence of deposits of an abnormal protein called amyloid. This systemic disease can affect the heart, nervous system, liver and kidneys. Within the kidneys, the amyloid is usually deposited in the walls of the kidney arteries and the glomeruli's blood vessels. This may result in abnormally high levels of protein in urine and can lead to progressive kidney disease.

MULTIPLE MYELOMA

This is a cancer of plasma cells. Plasma cells are a type of white blood cell present in your bone marrow. Multiple myeloma may cause kidney problems, including kidney disease. Higher calcium levels in the blood, due to damage to the bones caused by the myeloma, can interfere with the kidneys' ability to filter your bloods waste. The proteins produced by the myeloma cells can cause similar problems, especially if you become dehydrated.

VASCULITIS

This term refers to a group of diseases characterised by inflammation of the blood vessels. Vasculitis causes changes in the walls of the blood vessels, resulting in thickening, weakening, narrowing and scarring. It is usually due to the body producing antibodies that attack blood vessels throughout the body. Vasculitis may affect blood vessels of any type, size or location and, therefore, may cause dysfunction in any organ system, including the kidneys, lungs, skin and joints. Some of the types of vasculitis which can cause kidney dysfunction include:

- **Henoch Schonlein Purpura**
- **Microscopic Polyangitis**
- **Polyarteritis Nodosa**
- **Wegeners Granulomatosis**

A blood test called ANCA is commonly positive in vasculitis and is used to monitor the activity of this disease. Vasculitis can be very successfully treated, particularly if diagnosed early and treated with powerful immuno-suppressive medications.

These medications include high doses of steroids, cyclophosphamide, CellCept, and Azathioprine.

"Plasma cells are a type of white blood cell present in your bone marrow."

POLYCYSTIC KIDNEY DISEASE (PCKD)

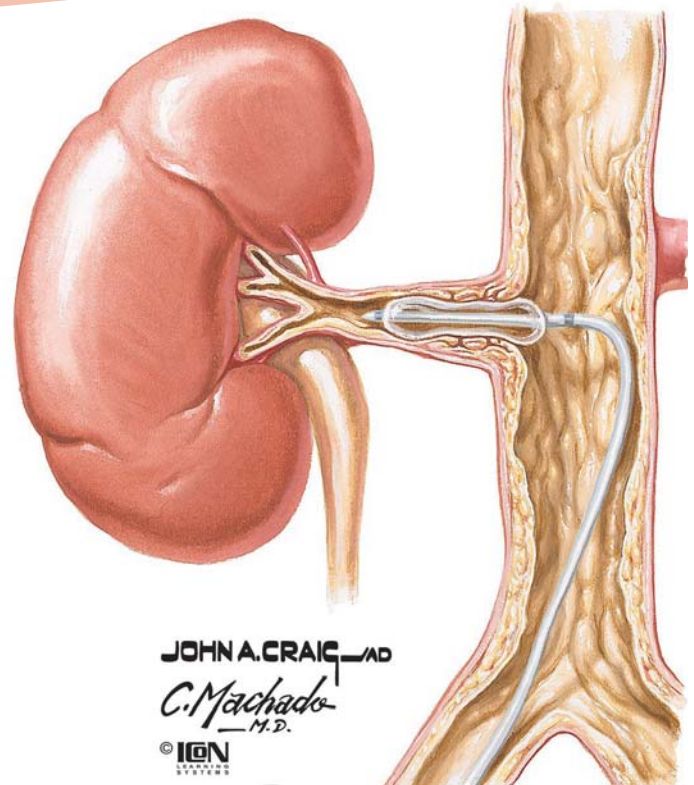
This is a *genetic* disorder characterised by the growth of numerous cysts within the kidney. These cysts are non-cancerous round sacs of water-like fluid. PCKD cysts can slowly replace much of the mass of the kidney, reducing kidney function and leading to kidney disease. People with PCKD may also have similar cysts in their liver, and there is also sometimes an association with a weakness of some of the blood vessels in the brain. PCKD is the most common inherited kidney disease, and children of parents with PCKD have a 50% chance of being affected by it. PCKD frequently causes kidney disease in patients in their 50's. PCKD is diagnosed by a ultrasound scan of the kidneys. Apart from control of blood pressure, there is no "cure" to stop the development of PCKD.

VASCULAR DISEASES OF THE KIDNEY

KIDNEY ARTERY STENOSIS This is a narrowing of the lining of the main artery (blood vessel) that supplies the kidneys. The resulting restriction of blood flow to the kidneys might lead to reduced kidney function and high blood pressure.

This type of hypertension is known as renovascular hypertension and accounts for approximately 5% of patients with hypertension.

Renovascular hyper-tension occurs when the artery to one of the kidneys is narrowed (unilateral stenosis). Kidney disease occurs when the arteries to both kidneys are narrowed (bilateral stenosis). The decreased blood flow to both kidneys increasingly impairs kidney function. This condition may be amenable to treatment with a balloon to open the blocked artery.



OBSTRUCTIVE DISORDERS OF THE KIDNEY

Obstructive Nephropathy - is a kidney disease caused by a blockage to urine flow through the urinary tract. There are many things that can block urine flow. Some of the more common causes include:

- Kidney Stones
- Enlarged Prostate Gland or Prostate Cancer (males)
- Bladder Problems
- Bladder Cancer

Obstruction of the urinary tract results in increased back pressure on the kidneys and increased frequency of urinary tract infections.

These factors cause recurrent episodes of kidney inflammation and scarring, and the kidneys may shrink (atrophy). If the blockage is only for a short time, the kidney can usually recover completely when the blockage is relieved. However, if the blockage is there for a long time (for many days or weeks), it can cause permanent kidney damage.

Pyelonephritis This is a bacterial infection of one or both kidneys. Chronic pyelonephritis is kidney damage caused by recurrent or persistent kidney infections. Chronic pyelonephritis is associated with progressive scarring of the kidneys, which can lead to kidney disease. It occurs mainly in patients who have malformations within the urinary tract.

Kidney Disease

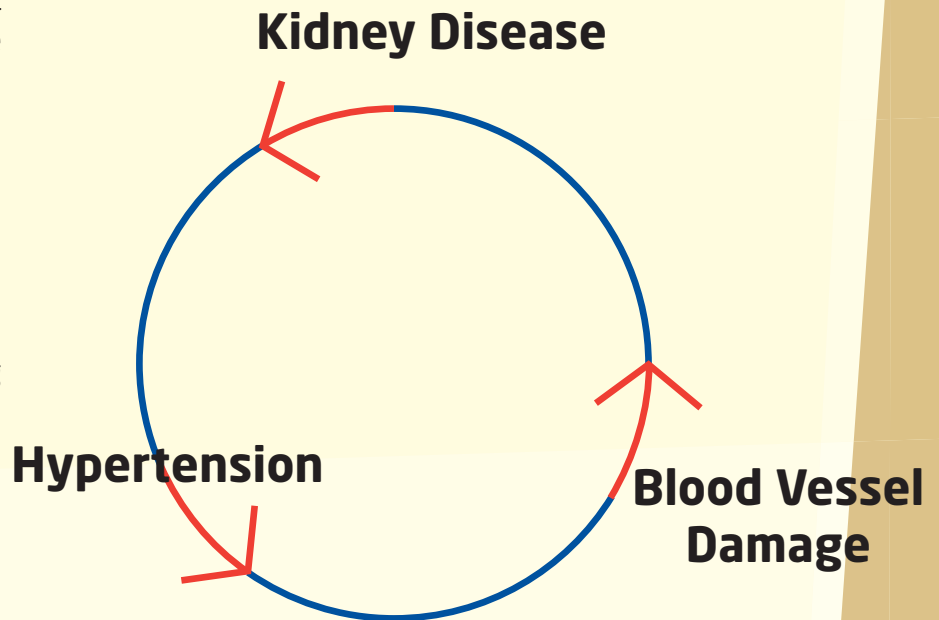
– A Guide for Patients

PROGRESSIVE KIDNEY DISEASE

There are many factors that can affect the rate of decline in kidney function.

THESE INCLUDE:

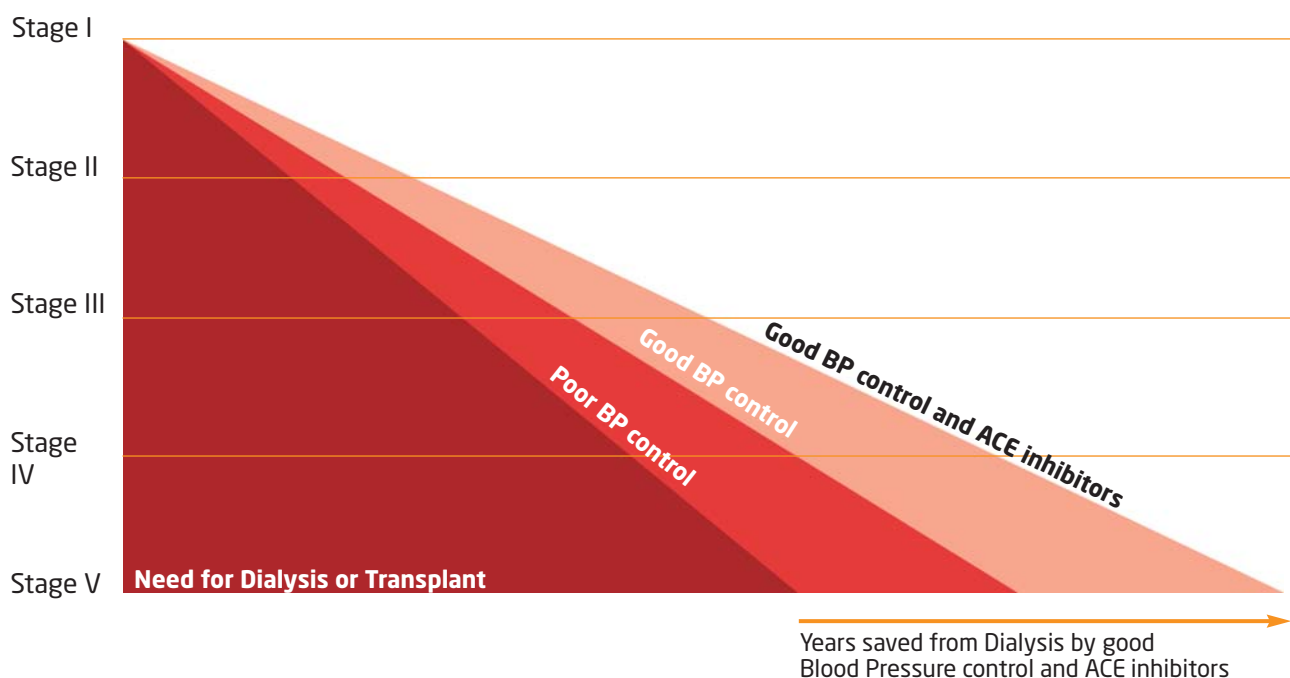
- Underlying cause of kidney disease.
- Blood pressure control
- Use of certain anti-hypertensive drugs, such as Angiotensin Converting Enzyme (ACE) inhibitors.
- The success of blood glucose control, in patients with diabetes.
- Control of cholesterol level.



Blood pressure control is one of the factors that can have the biggest influence in slowing the progression of kidney disease. The target blood pressure for any patient with kidney disease should be around 120/80 mmhg. The use of blood pressure medicines called angiotensin, converting enzyme inhibitors or angiotension II blocking inhibitors, has a considerable benefit in slowing progression of kidney disease. Examples of these medicines would include:

● Captopril ● Quinapril ● Enalapril ● Valsartan ● Losartin

Impact of Strategies to slow progression of Kidney Disease



Years saved from Dialysis by good Blood Pressure control and ACE inhibitors

SYMPTOMS OF KIDNEY DISEASE

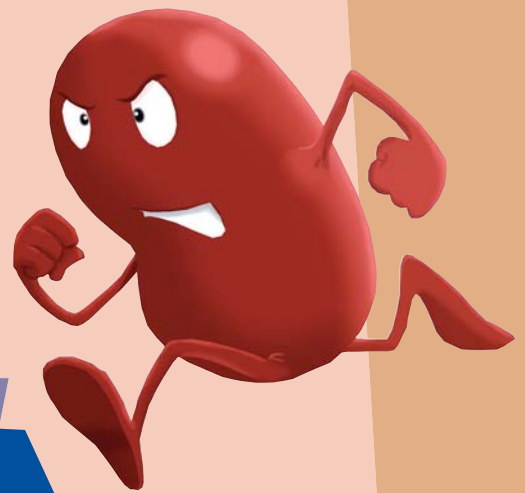
Independent of the cause of initial kidney injury, kidney function may continue to slowly deteriorate. This is associated with high blood pressure, worsening proteinuria and rising serum creatinine. Many people who have Chronic Kidney Disease (CKD) do not know it because the early signs can be very subtle. It can take many years to go from CKD to End Stage Kidney Disease (ESKD). Some people with CKD live out their lives without ever reaching ESKD.

In fact, the majority of people with kidney disease have no symptoms when first diagnosed and are diagnosed on the basis of blood or urine tests.

However, for people at any stage of kidney disease, knowledge is power. Knowing the symptoms of kidney disease can help you get the treatment you need to feel your best.

SYMPTOM 1: **CHANGES IN URINATION**

Kidneys make urine, so when the kidneys are failing, the urine may change. How? You may have to get up often at night to urinate. Urine may be foamy or bubbly. You may urinate more often, or in greater amounts than usual, with pale urine. You may urinate less often, or in smaller amounts than usual with dark coloured urine. Your urine may contain blood. You may feel pressure or have difficulty urinating.



WHAT PATIENTS SAY:

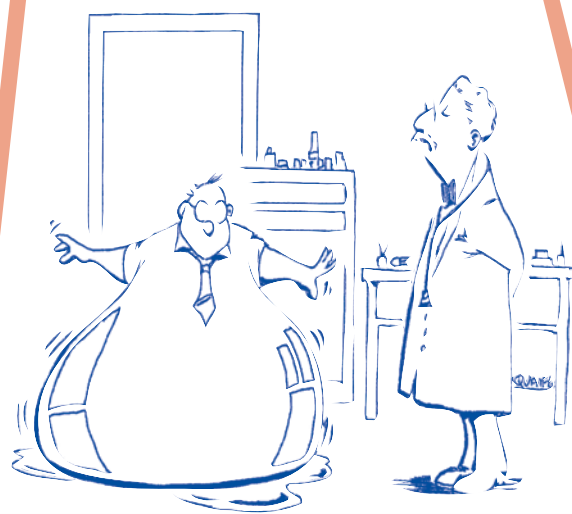
*"My urine is what I started noticing first.
I would frequently want to go to the bathroom
and when I got there I could only pass a few drops."*

SYMPTOM 2: **SWELLING**

Failing kidneys don't remove enough fluid which then builds up in your body causing swelling in the legs, ankles, feet, face and hands.

WHAT PATIENTS SAY:

*"I had a lot of swelling
in my ankles.
My ankles were so big
I couldn't get my shoes on."*



© 2007 Jazz Communications Limited

*Your tests reveal that
you are retaining fluids!*

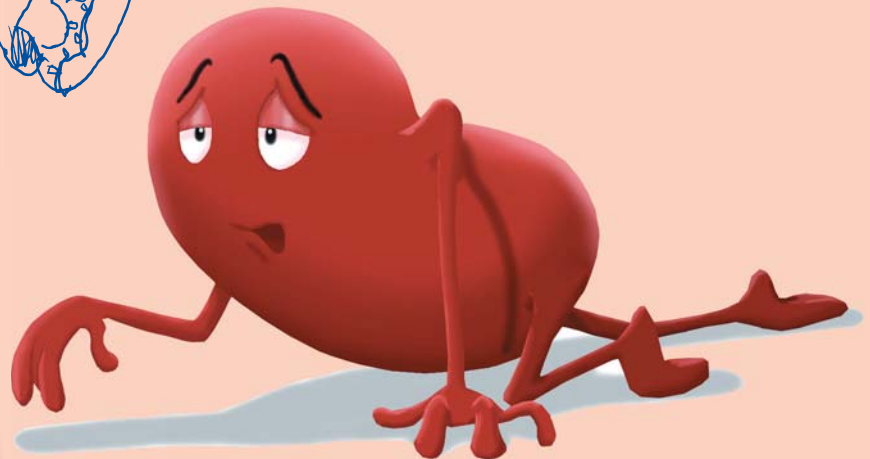
Kidney Disease

– A Guide for Patients

WHAT PATIENTS SAY:
"Fatigued, and you're just drained, even if you didn't do anything."



WHAT PATIENTS SAY:
"I would sleep a lot. I'd come home from work and get straight into bed."



SYMPTOM 3: **FATIGUE**

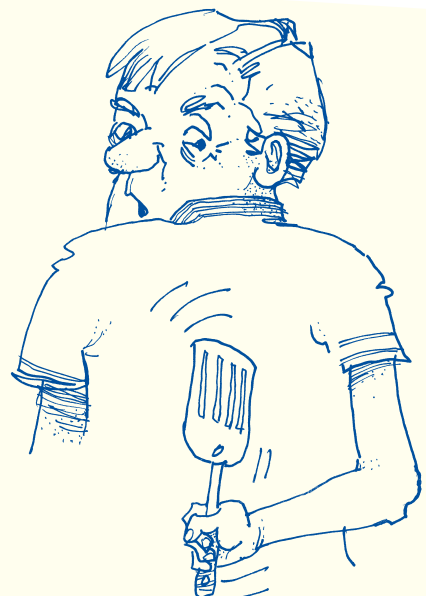
Healthy kidneys make a hormone called erythropoietin that tells your body to make oxygen-carrying red blood cells.

As the kidneys fail, they make less erythropoietin. With fewer red blood cells to carry oxygen, your muscles and brain become tired very quickly. This condition is called anaemia which can easily be treated.

SYMPTOM 4: **SKIN RASH/ ITCHING**

Kidneys remove waste from the blood stream. When the kidneys fail, the build-up of waste products in your blood can cause severe itching.

WHAT PATIENTS SAY:
"It's not really a skin itch or anything, it's just right down to the bone. I was itching and scratching a lot."



WHAT PATIENTS SAY:
*"Foul taste in your mouth.
Almost like you're
drinking iron."*

SYMPTOM 5:
METALLIC TASTE IN MOUTH/AMMONIA BREATH

A build-up of waste products in the blood (called uraemia) can make food taste different and cause bad breath. You may also notice that you stop liking to eat meat, or that you are losing weight because you don't feel like eating.

WHAT PATIENTS SAY:
*"You don't have the appetite
you used to have."*

SYMPTOM 6:
NAUSEA AND VOMITING

The severe build-up of wastes in the blood (uraemia) can also cause nausea and vomiting. Loss of appetite can lead to weight loss.

WHAT PATIENTS SAY:
*"When I got the nausea, I couldn't
eat and I found it difficult to
swallow my tablets."*



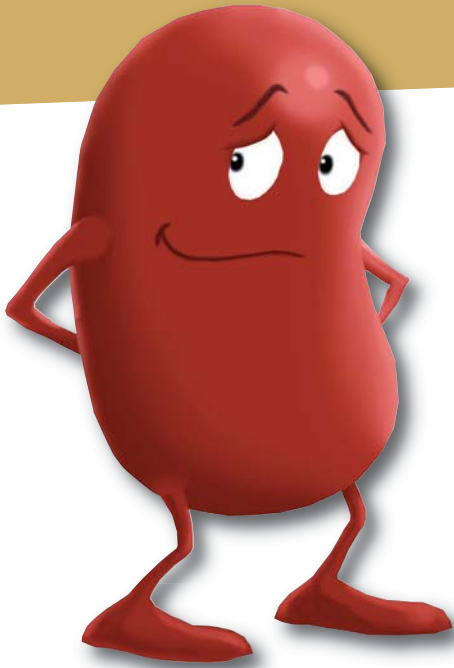
WHAT PATIENTS SAY:
*"I couldn't sleep
at night because
when I lay down flat,
I couldn't catch my
breath."*

SYMPTOM 7:
SHORTNESS OF BREATH

Trouble catching your breath can be related to the kidneys in two ways. Firstly, extra fluid in the body can build up in the lungs. And secondly, anaemia (a shortage of oxygen-carrying red cells) can leave your body oxygen-starved and short of breath.

WHAT PATIENTS SAY:
*"You go up a set of stairs and you're
out of breath, or you do work and
you get tired and you have to stop."*

Kidney Disease – A Guide for Patients



WHAT PATIENTS SAY:

*"I noticed sometimes
I get really cold
like chills."*

SYMPTOM 8: FEELING COLD

Anaemia can make you feel cold all the time, even in a warm environment.

WHAT PATIENTS SAY:

*"My memory disimproved a lot -
I couldn't remember what I did last
week or maybe 2 days ago.
I couldn't really concentrate
on my crossword puzzles
or reading."*

SYMPTOM 9: DIZZINESS AND TROUBLE CONCENTRATING

Anaemia related to kidney disease means that your brain is not getting enough oxygen. This, combined with uraemia, can lead to memory problems, trouble with concentrating, and dizziness.

SYMPTOM 10: FLANK PAIN

Some people with kidney problems may have pain in the back or side related to the affected kidney. However, most patients with kidney disease do not experience any pain at all.



CHAPTER 3

DIAGNOSTIC TESTING

WHAT ARE DIAGNOSTIC TESTS?

Diagnostic tests are used by doctors in order to better assess your health situation. These tests can be used to help establish your initial diagnosis, assess the effectiveness of the treatment you are receiving and/or detect potential complications. Some tests are simple, so simple that often you are unaware that they are happening, like a dipstick analysis of a urine sample. Other diagnostic tests are obvious enough for you to be aware of – like having your blood pressure, temperature and pulse checked. Another group of diagnostic tests considered to be low-risk and non-invasive include x-rays or ultrasound scans.

As soon as the requirements of a specific test involves entry of a needle or a probe into your body, they are considered to be 'invasive'. These tests include procedures such as blood tests, kidney biopsy or x-rays that require an injection of a dye.

WHY ARE DIAGNOSTIC TESTS IMPORTANT?

Diagnostic tests are often an important part of establishing what your health problem is in order that your doctor and nurse can deliver the treatment and care that will best suit your health care needs. The doctor can use other assessment skills to assist in this problem-solving process. These skills involve drawing conclusions from a person's medical history and performing a physical examination. However, a diagnostic test is often required to establish a diagnosis, to plan an intervention, or to monitor progress.

URINE TESTS

What does a dipstick urine test show?

A dipstick urine test, also known as a urinalysis, is a very simple test that is commonly done in clinics or when admitted to the hospital. You will be supplied with a sterile container and asked to carefully pass urine into the container to avoid the sample being contaminated. A nurse will insert, into the urine sample, a special strip that can detect protein, blood, white blood cells and glucose, in the urine, according to the changing colour of the strip.

Protein – this is an important building block in the body. When your kidneys are damaged, protein leaks into your urine (proteinuria). Persistent protein in the urine suggests damage to your kidneys.

Blood – The sample will be examined for colour and clearness. If blood is present, the urine may look red or the colour of cola. This may indicate an infection.

White Blood Cells – Presence in urine indicates infection.

Glucose (sugar) – Presence in urine may indicate diabetes.



Dipstick urine test

Kidney Disease

– A Guide for Patients

WHAT IS URINE CULTURE AND SENSITIVITY?

This is a 'mid-stream' urine sample. Do not collect the first or last part of the urine that you pass, which may contain bacteria or cells normally found on the skin. This is then sent to the laboratory to be examined under a microscope, which can help to diagnose some kidney diseases.

Many things can be seen - like red blood cells this can be a sign of kidney disease that damage the filtering units of the kidney, allowing blood cells

to leak into the urine.

It may also indicate other problems such as kidney stones. White blood cells, crystals, and bacteria can also be detected if there are bacteria or white blood cells and this may suggest urine infection. To confirm this, bacteria are allowed to grow on special plates overnight (culture). This allows the doctor to prescribe the most effective treatment for you.

24 hour
urine
collection
bottle



24 HOUR URINE COLLECTION

Kidney function is most precisely measured by calculating the Glomerular Filtration Rate (GFR). This is a precise estimate of the level of kidney function and can predict the time when kidney replacement therapy is likely to be needed. GFR can be determined by doing a 24 hour urine collection and a blood test. You may be asked to complete the urine collection, at home, or when admitted to hospital.

You will be given 1-2 large urine collection bottles and asked to collect your urine over 24 hours. It is important to discard the first urine sample of the day into the toilet and then collect all urine for the next 24 hours into the bottle(s). On the second day, the first sample of urine should be collected. The collection is then complete. A blood test is taken when the urine collection is completed. It is important that the collection is properly carried out or the results will be wrong.

PROTEIN-CREATININE RATIO

Urine protein testing is used to detect protein in the urine to help evaluate and monitor kidney function and to detect and diagnose early kidney damage and disease. A protein to creatinine ratio is a snapshot of how much protein is present, in the urine, at the time it is collected.

There are many different reasons why there is

protein in the urine. This test may be ordered on a random urine sample if a person shows evidence of significant and persistent protein in their urine or has known kidney damage that the doctor wishes to monitor. It is collected by either a 24 hour urine collection or a midstream urine sample.

BLOOD TESTS

Blood tests are regularly carried out to measure how well your kidneys are working.

The table on the next page outlines some of the blood tests that will be performed and what they mean.

BLOOD SAMPLE	NORMAL LEVELS	WHY IT IS BEING MEASURED
Urea (Ur)	2.5-8.5 mmol/L	A waste product produced in the liver and excreted by the kidneys. High values might mean the kidneys are not working as well as they should.
Creatinine (Cr)	49-90umol/L	A waste product produced largely from muscle breakdown. High levels, especially with high Urea levels, indicate problems with the kidneys.
Sodium (Na)	135-145mmol/L	The balance of salt and water in the body.
Potassium (K+)	3.2-5.2mmol/L	Important for proper functioning of nerves and muscles, particularly the heart. High and low levels require medical evaluation. Potassium comes from food, especially fruit, vegetables and nuts.
Calcium (Ca)	2.12-2.62mmol/L	Excreted by the kidney. Important for muscle contraction, cardiac function and blood clotting.
Phosphate (P04)	0.7-1.5mmol/L	Excreted by the kidneys. Necessary for strong bones, teeth, normal functioning of muscle and blood clotting.
Albumin	30-50g/L	Protein in the blood made in the liver. Low levels may indicate that protein is leaking into the kidneys or if someone is malnourished.
RISKS Cholesterol	0.00-5.00mmol/L	Measures how much cholesterol and lipids are present in your blood.
Triglyceride	0.000-1.90mmol/L	
Urate	140-420umol/L	
Parathyroid Hormone	15-65pglm	Concerned with the regulation of extra-cellular calcium levels.
Iron Studies Ferritin	18-240nglml	Main stored iron found in all tissues.
Complete Blood Count (CBC)	13.0-16.0gm/dl	Complete blood count is the red protein in blood. It carries oxygen around the body. One of the kidneys function is to produce erythropoietin (EPO), which stimulates the bone marrow to produce red blood cells. When kidneys fail it may be necessary to give EPO in the form of an injection.
White Cell Count (WCC)	4-11 10 ⁹ /l	White blood cells fight infection in the body. Raised/low levels may indicate infection.
Hepatitis B+C	Positive/Negative	Checks for the presence of hepatitis infection.

Kidney Disease

– A Guide for Patients

PLAIN ABDOMINAL X-RAY

A plain abdominal x-ray is used to show the kidneys, urethra and bladder (KUB). It also indicates the size, shape, position and the presence or absence of one or both kidneys.

What preparation is required?

There is no preparation required for this test.



Kidney Ultrasound Scan

KIDNEY ULTRASOUND SCAN

This is a non-invasive procedure where a transducer (sonar probe) is moved in close contact over the skin over the area of investigation and it can be repeated frequently if necessary. Ultrasound is used to determine the size and shape of the kidneys, to check both kidneys are present, location of kidneys and is useful in detecting cysts.

What preparation is required?

You will be asked to wear a hospital gown. Depending on the area of ultrasound you may be asked to fast prior to the procedure. Your doctor/nurse will inform you if this is necessary.

There are no risks attached to this procedure.

COMPUTERISED TEMOGRAPHY (CT SCAN)

A CT scan, also known as a CAT scan, is a specialised x-ray which provides clear pictures of the inside of your body. In particular, it can give good pictures of soft tissues of the body which do not show on ordinary x-ray pictures.

What preparation is required?

You will be provided with a hospital gown to wear during the procedure. Any jewellery will need to be removed and depending on what area is being scanned you may need to fast prior to the procedure. Your doctor/nurse can inform you if it is necessary. Also, it may be necessary to drink special fluids prior to the procedure. This is needed if you are having an abdominal/pelvic scan. This drink helps to show the stomach and bowel more clearly. Sometimes a dye (contrast medium) is injected into the bloodstream via a needle. The dye

may give you a flushing feeling and an odd taste in your mouth for a short time. Your doctor will prescribe a course of medication (n-acetylcystine) to take on the day before the scan, the day of the scan, and the day after. This medication protects your kidneys from becoming damaged from the contrast dye that is used during this procedure.

The scan is painless, however, it may take a little time to obtain the necessary pictures.



ECHOCARDIOGRAM

An echocardiogram is an ultrasound scan of your heart. The scan can give clear pictures of the heart muscle, heart chambers and structures within the heart such as the valves. Electrodes will be placed on your chest to allow for a tracing of your heartbeat during the procedure. Some cold gel will be spread on your chest and a transducer is placed on your ribs near your breastbone and directed towards your heart. The transducer will pick up the echos of the sound waves which transmit them as electrical impulses. The echocardiography machine converts these impulses into moving pictures of the heart. During the procedure you may be asked to breathe in a certain way and change your position.

What preparation is required?

No specific preparation is required and there are no risks attached to having this procedure performed. After the test is completed you can continue as normal.

Kidney Disease

– A Guide for Patients

ANGIOGRAM

An angiogram is a test, using dye and x-ray, to detect if there are any problems in the arteries, valves or chambers of the heart. This test might be performed if you experience tightness or pain in the chest, jaw or arm. A catheter is inserted via the femoral artery (top of the leg) and fed into the bigger artery. The contrast dye is injected and a number of x-rays is taken. You can have an angiogram of your coronary (heart) or renal (kidney) arteries.

Complications of this test include bleeding and a formation of bruising at the catheter site, or occasionally, further deterioration of kidney function.



Angiogram

What preparation is required?

Your doctor will explain the procedure to you and will ask you to sign a consent form to state that you understand the procedure and possible complications. Some complications may include irregular heart rhythms, chest pain, allergic reaction to the dye, bleeding at the groin site and, very rarely, heart attack or stroke.

You will be asked to remove your jewellery and be provided with a hospital gown. It will be necessary to take some blood samples, which will be sent to the laboratory, to ensure it is safe to perform this procedure. Your doctor will also place a needle into your vein (cannula). It may be necessary for you to take medication (n-acetylcystine), prior to this test, to protect your kidneys from the dye that is required for the test.

What will happen after the procedure?

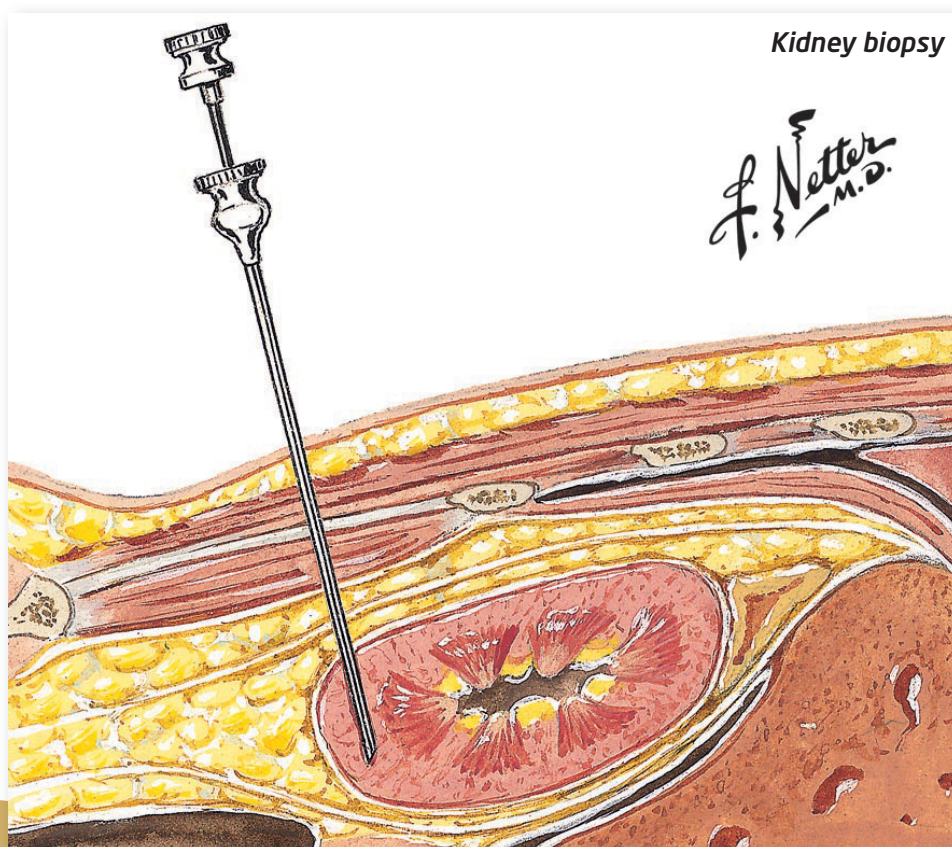
After the procedure, you will be asked to remain on bed rest for 6 hours to allow the puncture site to heal completely. You will need to drink plenty of fluids for the following 24 hours providing you are not on fluid restriction. This will help to flush the dye from your system. A bedpan/urinal will be provided if required. It is very important that you do not bend your leg or sit up before your rest time is over. The nurse will be checking your blood pressure, pulse and the site where the procedure was carried out. Inform the staff if you have pain or discomfort as pain medication can be given.

Your doctor will discuss your results with you before you leave the hospital or at your next appointment. It may be necessary to commence some medication or go for further tests, depending on your results.



KIDNEY BIOPSY

A kidney biopsy is an important test to either establish why the kidneys have stopped working properly or to confirm a diagnosis of rejection in transplant patients.



What preparation is needed?

You are admitted to the ward the day before or to kidney day care at 07.30am on the morning of your biopsy. You will be asked to fast from 12 midnight the night before the procedure. Your blood pressure will be checked and a blood sample taken to ensure that it is safe to proceed.

The doctors will discuss the complications to you and obtain a written consent. The doctor will instruct you on any medications that need to be stopped prior to the procedure e.g. warfarin.

Kidney Disease

– A Guide for Patients

How is the procedure performed?

A kidney biopsy is carried out in the x-ray department or on the ward by the nephrologist. Mild sedation may be given prior to the procedure. If the biopsy is of your native kidney, you will be asked to lie on your tummy.

If the biopsy is of your transplant kidney, you will be asked to lie on your back. This allows the doctor easier access to the kidneys. The skin will be cleaned with antiseptic solution and a local anaesthetic will be given to numb the area. A special biopsy needle is introduced through the skin into the kidney to take the sample. Two or three samples might be required.

“Following the biopsy, you must stay in bed for 6 hours. This is to allow the puncture site to stop bleeding and help prevent any complications.”

It is advisable to avoid any strenuous exercise for a week after the biopsy to reduce the risk of bleeding. After this there should be no reason why normal activities cannot be resumed.

If you experience severe pain over the biopsy area or notice blood in your urine, you should report back to your doctor.

What happens after the biopsy?

Following the biopsy, you must stay in bed for 6 hours. This is to allow the puncture site to stop bleeding and help prevent any complications. Following the 6 hour period, you may mobilise gently to the bathroom only. Full mobility can resume the following morning if no complications have occurred. Your blood pressure and pulse will be monitored regularly and the biopsy site dressing checked. Each time you pass urine, it should be given to the nurse, who will then test it to see if there is any bleeding. Painkillers will be prescribed if you need them.

You will be able to eat and encouraged to drink plenty of fluids (providing you are not on fluid restriction). You will be discharged the following morning if no other procedure or treatment is scheduled for you.

What are the possible complications during a kidney biopsy?

Any medical or surgical procedure carries risks. Patients are asked to undergo procedures because it is felt that the benefits outweigh the risks. Complications of kidney biopsy are rare. The most important is bleeding, and you are closely monitored after the biopsy to detect bleeding.

You may have pain or discomfort after the biopsy. Painkillers can be taken to reduce any discomfort. If you experience severe pain, after the biopsy, you should contact the kidney unit.

Other possible complications of kidney biopsy include:

- Bleeding into the kidney, which can result in loss of the kidney;
- Persistent haematuria (blood in your urine);
- Biopsy of an organ other than the kidney;
- Rupture of the kidney;
- Death (**extremely** rare).

When do I get the results?

It takes up to 48 working hours for the laboratory to give a preliminary report and about a week to ten days to get a full written report. Your doctor will discuss the results of the biopsy with you and discuss appropriate treatments if required.

CHAPTER 4

DIETARY ADVICE FOR KIDNEY PATIENTS

Dietary treatment is an important aspect of care for all patients with kidney disease. It is necessary to meet with your dietitian to discuss individual needs for your renal diet.

The following information will give you an overview of a renal diet, prior to dialysis, and also what to expect when you commence dialysis. You will be informed by the dietitian when it is necessary to commence this diet. All patients have different dietary needs, so it is important to start this diet only under the guidance of the dietitian.

A healthy balanced diet contains correct amounts of protein, carbohydrate, fat, vitamins and minerals. It is important that your diet is balanced and varied to keep you in optimum health.

Some of the main functions of the kidney that relate to the diet include:

- Excretion of waste products;
- Control of fluid volume in the body;
- Control of blood pressure.

When food and drinks are consumed, our bodies use what is needed and the rest is turned into waste products which can be excreted as urine. When your kidneys are not working properly, these waste products can build-up in your blood and cause complications, which will be discussed in the following sections.

FOODS TO ENJOY



Kidney Disease

– A Guide for Patients

SALT

Salt is an important aspect of dietary treatment at all stages of your kidney disease. High intake of salt, from the diet, can cause problems with blood pressure control and fluid retention. It is advised to avoid adding any salt to meals and also to reduce the intake of very salty foods such as processed meats, bacon, sausages, soup and packet sauces. Your dietician will advise you on suitable alternatives to using salt.



FOODS TO AVOID

PROTEIN

Protein intake from the diet is important during the progression of chronic kidney disease and also when you commence dialysis. The protein we eat is used for tissue repair and growth. Any unused protein is broken down into waste products, including urea and creatinine. As your kidneys are unable to excrete urea and creatinine properly, they build up in your blood and cause symptoms such as nausea and loss of appetite.

By eating large amounts of protein foods e.g. meat, fish, chicken, eggs, cheese, milk and yoghurt before commencing dialysis, you will affect the build-up of urea and creatinine in your blood. An appropriate daily intake of protein should be advised by your dietician.

However, once dialysis treatment has commenced it is important to make sure that your body is getting enough protein to prevent malnutrition. Some of your stores of protein are lost during the haemodialysis and CAPD sessions.

How much protein you need depends on your body size and is specific to each individual.

PHOSPHATE

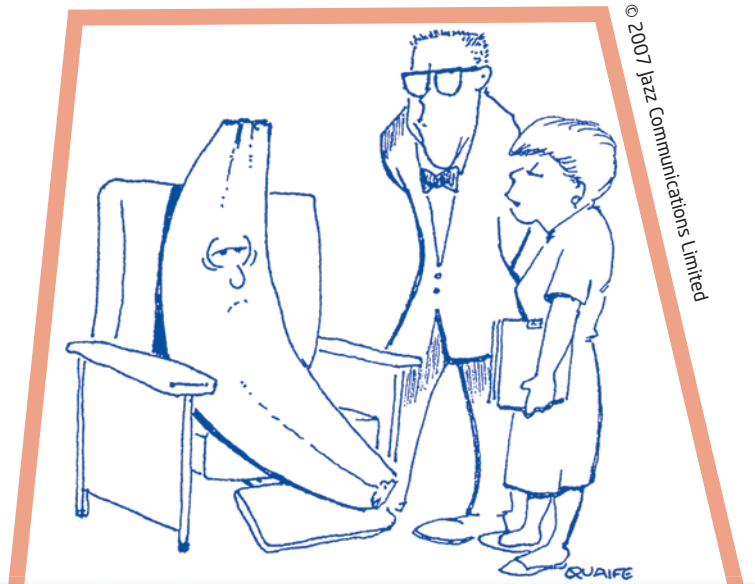
Phosphate is another mineral found in many foods, mainly meat and dairy products such as milk, cheese, yoghurts, and also bran nuts and cola. Calcium and phosphate work together to keep your bones, teeth and blood vessels healthy. When phosphate and calcium levels are elevated, or out of balance in kidney disease, the extra calcium and phosphate join together to form hard deposits in your body. This is known as calcification. These deposits can form in the heart, lungs, blood vessels, joints and other soft tissue. High phosphate levels also affect your bones, causing kidney bone disease. Over time bones become brittle, weak and painful and liable to fracture easily.

As with potassium, an elevated phosphate level will require you to reduce the intake of phosphate from your diet. It may also be necessary to take phosphate binding substances with your food to reduce the absorption of phosphate from the gut.

POTASSIUM

Potassium is a mineral found in many foods, mainly fruits, vegetables and potatoes. It is necessary for muscle contractions but a very high level in the blood can be dangerous as it may cause irregular heart rhythm. If your potassium levels increase, above normal, you will need to avoid certain foods that are high in potassium as advised by your dietician. High sources of potassium in the diet include bananas, dried fruit, peas, beans, spinach and potato products such as chips and crisps.

The dialysis diet provides enough potassium to meet the needs of your body, while preventing accumulation between dialysis sessions.



© 2007 Jazz Communications Limited

*We're a little concerned
about your potassium levels*

FLUIDS

If you are treated with haemodialysis or peritoneal dialysis you may need to limit your fluid intake. The amount of fluid you will be allowed depends on the amount of urine you produce. You can reduce your fluid intake by using small cups/glasses, and spacing out your drinks throughout the day. You can also help prevent thirst by limiting the amount of salt and salty foods that you eat.

Each person, with kidney disease, is very different and so are their needs and requirements. The dietary advice you are given depends on a number of factors including the stage of kidney disease, the type of treatment you are on, your blood results, your body weight, and the presence of other medical conditions e.g. diabetes mellitus, high cholesterol levels. The dietician will, therefore, provide you with information that is designed for you as an individual to suit your own specific needs.



Truly Tasty

Over 100 special recipes created by Ireland's top chefs, for adults living with kidney disease. Perfect for entertaining or for planning that special meal that is suitable for all to enjoy.

ORDER YOUR COPIES NOW.

www.trulytasty.ie

Kidney Disease

– A Guide for Patients

GUIDE TO SUITABLE FOODS TO USE WITHIN YOUR RENAL DIET:

Foods Low in Potassium	Foods High in Potassium
✓ Apples, pears, plums, mandarins, grapes	✗ Banana, dried fruit, prunes, apricot,
✓ Kiwi, peach	✗ Rhubarb
✓ Cauliflower, peppers, carrots, broccoli	✗ Peas, beans, mushrooms, spinach, beetroot
✓ Cabbage, green beans, turnip	✗ Salt substitutes
✓ Boiled/mashed potato, rice, pasta	✗ Jacket/chipped/roast potato
✓ Spirits, white wine, boiled sweets	✗ Beer, stout, red wine, chocolate, coffee

Foods Lower in Phosphate	Foods High in Phosphate
Ask your dietician about milk alternatives	Milk, yoghurt, cheese
Porridge, Weetabix, Cornflakes, tea	Bran cereals, peas, beans, corn, nuts
Marshmallows, jellies, boiled sweets	Toffee, cola, chocolate

Foods to ENJOY	Foods to AVOID
Pepper, herbs, garlic, mustard, lemon	Salt, stock cubes, soup
Home-made stock	Salted snacks
Chicken, lamb, pork, beef, eggs	Bacon, sausage, black & white pudding
Fish (excluding smoked fish)	Processed meats
BREAKFAST	
Boiled/poached/fried eggs	Bacon, sausage, black & white pudding
Plain omelette, bagel, English muffin	Salt substitutes
Croissant, french toast, porridge,	Bran cereals, muesli
Cereals (excluding bran cereal & muesli)	
SANDWICH IDEAS	
Turkey and cranberry sauce	Ham, cornbeef, salami
Roast beef & mustard	Cheese
Egg mayonnaise, chicken, tinned salmon (no bones)	
MAIN COURSE	
Ask for sauces/gravy to be served on the side and use sparingly	Casseroles, cured or salted meats
Roast/grilled pork/lamb/beef	
Chicken/turkey or fish	
SIDE ORDERS	
Green beans, cabbage, asparagus	Spinach, mushrooms, peas, corn
Carrots, cauliflower, broccoli	Chipped/jacket potato
Plain rice, pasta, noodles, couscous	
DESSERT	
Canned peaches, pears, fruit cocktail	Dried fruit, fresh fruit cocktail, melon
Fresh grapes, fresh & canned pineapple	Banana, orange
Jelly, plain and cream cakes, apple tart	Desserts with chocolate, nuts, dried fruit
Sherbet, sorbet, plain biscuits, Pavlova	Coconut, milk pudding, ice cream

CHAPTER 5

MEDICATIONS



People with Chronic Kidney Disease (CKD) will find themselves on a variety of medications. These medications can be classified according to what they do and include the following:

These are just examples of some of the drugs available. Medications have different brand names so it is important to realise that different coloured medication may be given while in hospital.

- Phosphate binders
- Antihypertensive medications
- Diuretics
- Erythropoietin (EPO)
- Oral and intravenous iron

PHOSPHATE MEDICATIONS

Many of the foods you eat contain an element called phosphate. Foods particularly high in phosphate include all dairy products such as milk and also chocolate, pizza and bread. When kidneys fail they are not able to get rid of phosphate and it will build up in your body. It is necessary to take medications called 'phosphate binders'. There are a number of different phosphate binders available. They all work in the same way in that they bind phosphate in your stomach, which prevents the phosphate being absorbed into your circulation. **All phosphate binders are taken with meals.** This is the only way these tablets work and are of no benefit at any other time.

The available phosphate binders include:

Calcium containing compounds. These calcium tablets are effective at binding phosphate but, sometimes, can cause the calcium level in the blood to go too high. These tablets may cause constipation or gas. They are chewed and taken with meals.

Sevelamer (Renagel). This tablet is swallowed and not chewed. Frequently you may have to take as many as 3 tablets, 3 times a day. This tablet may also cause some constipation or abdominal discomfort. It has the advantage over other phosphate binders in that it does not contain calcium.

Foznol is also another phosphate binder commonly used.

Kidney Disease – A Guide for Patients

BLOOD PRESSURE MEDICATIONS

It is very important to control blood pressure - aiming to keep blood pressure as close to normal as possible. There are many approaches to control blood pressure, including weight loss, salt avoidance, exercise and reduction in alcohol intake. Many patients will, however, also need to take blood pressure tablets. There are many different classes of blood pressure tablets including:



- Betablockers
- Calcium channel blockers
- Angiotensin converting enzyme inhibitors (ACE)
- Angiotensin receptor blockers (ARB)
- Alpha blockers

BETABLOCKERS

(e.g. Atenolol, Metoprolol, Bisoprolol)

Betablockers are amongst the most commonly prescribed blood pressure medications. Examples include Atenolol and Metoprolol. These tablets are used to treat cardiac conditions in addition to high blood pressure. Betablockers work by blocking the effect of adrenaline on blood vessels and the heart. Consequently, they will slow the heart a little. People with severe asthma need to be careful with these medications as they may make asthma worse and they may also, occasionally, make your hands feel cold. Occasionally, betablockers may give you nightmares.

CALCIUM CHANNEL BLOCKERS

(e.g. Istin, Dilzem)

Calcium channel blockers work by directly making blood vessels relax by blocking calcium going into muscles around the blood vessels. The commonest side-effect of these medications is swelling of the legs. They may also, occasionally, cause redness of the skin.

ALPHA BLOCKERS

Alpha blockers work by blocking the function of adrenaline on blood vessels. Occasionally these medications may cause you to become dizzy when you stand up.

ANGIOTENSIN CONVERTING ENZYME INHIBITORS (ACE) AND ANGIOTENSIN RECEPTOR BLOCKERS (ARB)

One of the important hormones in the body that controls blood pressure in the body is called angiotensin. ACE inhibitors work by blocking the production of this hormone and ARB work by stopping the effect of angiotensin. These drugs are used to treat blood pressure and heart failure. They are also effective at slowing the decline in kidney function. ACE inhibitors may sometimes cause a persistent cough which resolves when the ACE is stopped. These medications may also cause the potassium levels to rise too high. Your bloods will be carefully monitored for this.

DIURETICS

(e.g. Lasix, Burinex)

Diuretics are medications that make you pass more urine. These medications are used to treat swelling of the legs, heart failure and are also commonly used to treat high blood pressure. Diuretics can also be prescribed for patients who are on dialysis which help produce more urine and gain less weight between dialysis treatments.

These medications will work for up to six hours after they are taken. Side-effects of diuretics include dehydration if they make you pass too much urine.



VITAMINS

When you have kidney disease you will have lower levels of vitamins in your body than you need, so you may need to take a number of different vitamins including:

- Multivitamins;
- Folic acid;
- Vitamin D.

MULTIVITAMINS

Patients, who are on dialysis, commonly lose much of the water soluble vitamins through the dialysis machine. It is important that you do not

take just any multivitamins as some of these preparations may contain too much of the fat soluble vitamins.

Folic acid is important for many of the metabolic functions of the body.

VITAMIN D

The kidney is responsible for converting the vitamin D that is in your body into the active form of vitamin D. People with kidney disease lack the ability to produce the active form of vitamin D. Vitamin D is important for the absorption of calcium and for bone health which is important to prevent

the parathyroid glands becoming overactive. As mentioned earlier the parathyroid (PTH) glands are small glands in your neck that control calcium levels in your body. People with kidney disease can have PTH levels that are too high. One of the major functions of Vitamin D is to lower PTH levels. Too much vitamin D may cause the calcium, in your blood, to go too high so your doctors and nurses will be carefully monitoring calcium levels by obtaining regular blood samples.



Kidney Disease

– A Guide for Patients

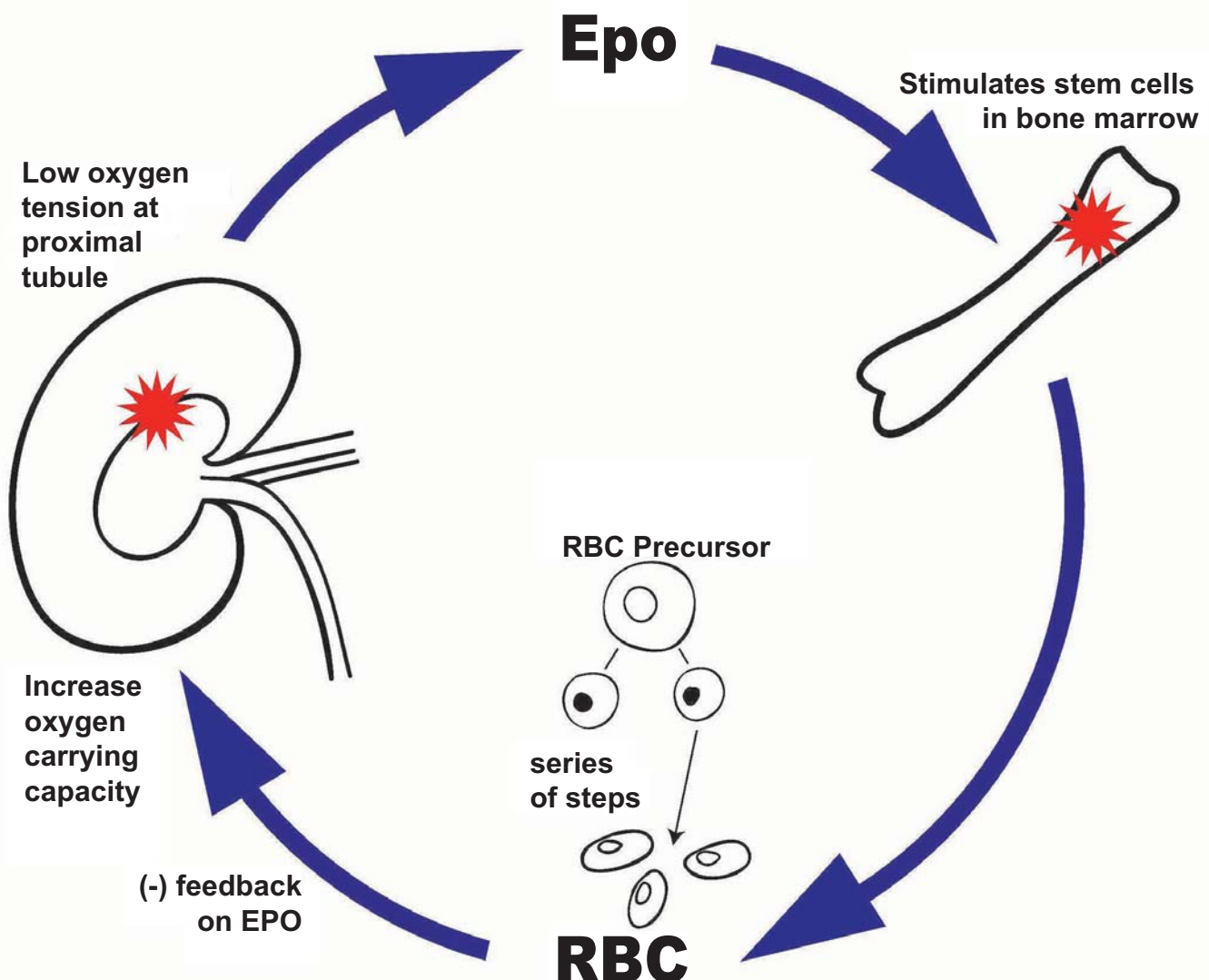
ERYTHROPOEITIN (EPO)

Patients with kidney disease very often have a low blood count. Under normal circumstances the kidney produces a substance called erythropoietin (EPO). EPO works on the bone marrow cells to make more blood cells. EPO needs to be administered by way of an injection. It cannot be taken as a tablet. The injection may be given as an injection directly into the dialysis machine or as an injection into the skin. EPO can be administered either once, twice or three times a week or sometimes every second week or, even only once a month, depending on your blood. Patients will feel much better on EPO as they will acquire more energy with a higher haemoglobin.

EPO is prescribed on a high-tech prescription.

Your chemist will give you 4 or 5 vials, which you will need to keep in the fridge (not the freezer). Your kidney nurse will either teach you how to administer the medication yourself or arrange a district nurse or your GP practice nurse to administer it. It is also possible to have your injection when you attend for dialysis.

It is important to stay on this medication until your doctor indicates otherwise. You will need frequent blood tests to monitor the effectiveness of the EPO as too much EPO may cause your blood to go too high or you may need to increase the dose if you are not getting enough benefit. It is important that you bring your medication with you on admission to hospital or for each dialysis treatment if required.



ORAL OR INTRAVENOUS IRON

EPO is extremely effective at increasing your blood count. However, in order for the EPO to work effectively your body needs to have enough iron. It is difficult for your body to take in enough iron through regular diet for the EPO to reach full effect. Your doctor may prescribe oral iron. Iron tablets can be a little unpleasant to take as they may make your stomach upset or cause you constipation. Iron tablets will also make your bowel movement black and tarry.

If you cannot tolerate iron tablets or your doctor determines, by blood test, that you are still low in iron, you may be prescribed intravenous iron. If you are on haemodialysis, you will be given iron directly into the dialysis circuit.

If you are on home dialysis or not on dialysis, you will need to come to Renal Day Care, 3rd Floor, for infusions of iron treatment. Intravenous iron is a safe drug but there is an occasional occurrence of an allergic reaction. So, before you get the first dose, you will generally receive a test dose (small dose).



PARATHYROID DRUGS

As we discussed under Vitamin D, your parathyroid glands are four small glands in your neck that control the level of calcium in your blood. In kidney disease, parathroid (PTH) hormone tends to increase. When this happens, it can have a number of effects, including weakening of your bones



and causing pain in your bones and joints. In the first instance, your doctor may give you vitamin tablets (Rocaltrol or One Alpha); however, if these do not work, it may be necessary to receive Vitamin D intravenously (Zemplar) directly into the dialysis machine. If these strategies are not adequate, your doctor may advise you to take another drug called Cinacalcit (Mimpara). This drug is extremely effective at lowering PTH level. The main side effect of Cinacalcit is that it may cause a little nausea after it is taken. This, generally, settles down after a few days.

Occasionally, if these drugs are not effective in controlling your PTH level, your doctor may recommend an operation to remove part of your parathyroid glands (a parathyroidectomy).

Kidney Disease – A Guide for Patients

CAUTION WITH COMMONLY USED DRUGS

When you have kidney disease, you need to be very careful with all your medications. You need to make sure your doctor knows that you have kidney disease before he prescribes you any new medications or alters your dose. Only take medication that is prescribed for you. Please inform your doctor or chemist if you plan to take herbal medication as some of these may interact with your regular medication. Similarly, you need to be very cautious of many 'over-the-counter' medications which are easily available. Some of these include:

- NSAIDS or anti-inflammatories should be avoided. Examples of these would include: Ponstan, Neurofen, Ibuprofen, Advil, Difene, Voltarol, etc.



For pain control you should take simple analgesics such as Panadol or Solpadeine. If you need something stronger, speak with your doctor.

It is very important that you know your medications and how they work. Your healthcare team will work alongside you to achieve this.



DRUGS TO AVOID

- ✗ Ponstan
- ✗ Neurofen
- ✗ Ibuprofen
- ✗ Advil
- ✗ Difene
- ✗ Voltarol

CHAPTER 6

INFECTION AND VACCINATION



CAUSES OF INFECTIONS

The common causes of Infections in Ireland are:

- **Bacteria** (e.g., salmonella, TB, E.Coli).
- **Viruses** (e.g., common cold, flu, winter vomiting bug).
- **Fungi** (e.g., thrush, athletes foot).

Infections are spread by:

- Air (e.g. TB, chicken pox).
- Droplet, sneezing and coughing (e.g., mumps, rubella, common cold).
- Direct contact (e.g., salmonella from eating uncooked chicken, and sexually transmitted diseases such as syphilis).
- Indirect contact (e.g., salmonella from a sandwich made by the unwashed hands of a person infected with salmonella).
- Vectors - e.g., mosquitoes spreading malaria.

Kidney Disease

– A Guide for Patients

PREVENTING INFECTION

The human body has developed general and specific defences against infection. General defences protect the body against all infections and examples include skin, secretions such as tears, cilia (tiny hairs), which filter air entering the lungs, and body washings, such as flow of urine from the bladder, which washes away bacteria with the urine.

Specific defences develop when the body's immune system produces antibodies against certain diseases. These antibodies develop after an infection (e.g., chicken pox) or after vaccination (e.g., whooping cough, rubella) and ensure that infection or re-infection very rarely occur.

People with kidney disease have an immune system that does not work as efficiently as normal. In addition, some complications of common illness such as pneumonia after flu can be dangerous for people with kidney disease. However, everyone can assist his or her natural immune system preventing infection by:

- Eating a well balanced diet and taking regular exercise
- Good general hygiene will help keep the skin in good condition
- Regular hand washing, especially before eating, and after using the toilet
- Attending for regular check-ups with your kidney specialist and GP will ensure that your kidney function and general health are maintained
- Attending your GP or the kidney unit promptly if you are not feeling well

INFECTIONS AND KIDNEY DISEASE

People with kidney disease are vulnerable to the same infections as the general population, such as flu, measles and mumps. However, they are more vulnerable to certain infections due to the treatments used (haemodialysis, peritoneal dialysis and transplantation) and due to regular hospital admissions (MRSA, VRE, and C.Difficile).

Infection complications associated with haemodialysis treatment

Haemodialysis treatment is known to be a risk for:

1. Bacterial infections associated with access, i.e., catheters, fistulas and grafts.
2. Blood borne viral infections (hepatitis B, C and very rarely HIV).

Access infections

See chapter 4 (Book 2 - *Haemodialysis and Peritoneal Dialysis - A Guide for Patients*) for detailed information on infection associated with access.

Blood borne infections associated with haemodialysis (HD)

Outbreaks of viral blood infections (Hepatitis B and C) have happened in haemodialysis units. As a result, our unit takes infection control very seriously indeed and make every effort to reduce the risk to an absolute minimum.

The measures include the following:

- All patients are screened on admission and routinely for hepatitis B & C & HIV
- All staff are vaccinated against hepatitis B
- All patients are strongly recommended to be vaccinated against hepatitis B
- Patients with known infections are treated in single rooms, on special machines.

All equipment used, on each patient, is either disposed of after each use or cleaned and disinfected after every use.

Infection complications associated with Transplantation

See chapter 8 (Book 3 - *Kidney Transplantation - A Guide for Patients*) for information on infection, associated with transplantation.

MRSA, VRE AND C.DIFFICLE

People who have regular hospital admissions, such as kidney patients, are at increased risk of acquiring MRSA, VRE and C.Difficile.

MRSA

What is MRSA?

MRSA is the shortened term used when referring to **M**eticillin **R**esistant **S**taphylococcus **A**ureus. Staphylococcus aureus (S. aureus) is the name of the bacteria. The sensitive strain is found in the nose and skin of 20-30% of healthy people. The resistant strain (MRSA) means that it cannot be treated with antibiotics normally used to treat the sensitive strain.

Where is MRSA found?

MRSA is most often found in hospitals or nursing homes where antibiotics are used frequently therefore encouraging the development of resistant strains of bacteria.

How does a person acquire it?

MRSA is transferred from one person to another by human contact. The main method is on hands, during patient care. Patients, who are carriers, may pass it on to other patients if they are in close contact.

Does MRSA make a patient more ill?

Some patients are colonised with MRSA and others have infections caused by MRSA. A patient is colonised with MRSA when he/she has no signs or symptoms of infection. It does not alter their treatment and is not a reason to stay in hospital.

MRSA infection, like other infections, varies from mild to severe and depends on other factors, such as where the infection is, and the patient age and underlying conditions. A person found to be colonised or infected with MRSA will be nursed separately from other patients, in a single room (isolation), or in a room with others who also have MRSA (co-horted).

What is the treatment for MRSA?

A patient, colonised with MRSA, is treated with special washes and ointments.

A patient, infected with MRSA, is treated with antibiotics, in tablet or by a drip into a vein.

VRE

What is VRE?

VRE is the short-term used when referring to **V**ancomycin **R**esistant **E**nterococci. Enterococci are bacteria found in the faeces of humans. Most of the time enterococci are part of the normal bacteria of the bowel and do not cause disease. A strain of enterococci has developed resistance to vancomycin, which is an antibiotic used to treat serious infections including MRSA infections.

Where is VRE found?

VRE is found in hospitals where patients are very unwell, such as intensive care, kidney and transplantation wards. Enterococci can survive on surfaces, ledges and floors.

How does a person acquire VRE?

VRE may be transferred from one person to another by direct contact, particularly from hands, during patient care.

Does VRE make a person more ill?

This varies from patient to patient. The majority of patients are colonised, whilst some are infected. Colonised means that the VRE is not causing infection. The presence of VRE colonisation does not alter their treatment and is not a reason to stay in hospital. VRE infections can vary from mild to severe and depends on factors such as the site of the infection and the patient's overall condition.

Patients with VRE, in a wound or in a urine specimen or those having diarrhoea, need to be nursed in a single room (isolation) or nursed in a room with other patients with VRE (co-horted).

What is the treatment for VRE?

Infection, with VRE, is treated with antibiotics usually given in a drip in a vein. Colonisation with VRE does not require any special treatment.

Kidney Disease

– A Guide for Patients

C. DIFFICLE (CLOSTRIDIUM DIFFICILE)

What is Clostridium Difficile (C. Diff)?

C. Diff. is a bacteria that causes diarrhoea and may cause intestinal conditions such as colitis. It is a common infection in hospitals and long-term facilities.

The use of antibiotics alters the normal bacterial content of the bowel and, thereby, increases the risk of developing C. Diff. diarrhoea.

Where is C. Diff found?

C. Diff is found in the bowel of some people and can also survive for a long time on surfaces.

How do people get C. Diff?

Healthy people are not at risk from getting C. Diff. People who have other illnesses or

conditions requiring prolonged use of antibiotics and the elderly are at risk of infection. They can become infected if they touch items that are contaminated and then touch their mouth.

Does C. Diff make a person more ill?

In most patients, the symptoms are mild and discontinuing treatment with antibiotics and fluid replacement results in rapid improvement. Sometimes, it is necessary to give a specific antibiotic, by mouth, for the condition. Unfortunately, 20-30% of patients relapse and need further courses of antibiotics.

Patients need to be nursed in a single room (isolation) or, in a room with other patients with C. Diff (cohorted), until bowel movement has returned to normal.

VACCINATIONS RECOMMENDED FOR PEOPLE WITH CHRONIC KIDNEY DISEASE
As prevention is always better than cure, the Department of Health and Children advise that certain vaccinations be given to people with kidney disease. Your kidney doctor or GP will advise you when you need to start getting vaccinated, but, in general, once a diagnosis of chronic kidney disease is confirmed, the vaccinations listed below should be given:

- **Pneumococcus** - This bacterium can cause serious infection in the lungs (pneumonia), the blood (bacteraemia) and covering of the brain (meningitis). Vaccination consists of a single injection, followed by a once-off booster dose 5 years later.
- **Influenza (flu)** - An annual flu vaccine is advised, as infection can be complicated by pneumonia, which is dangerous for people with chronic illness.
- **Hepatitis B** - Hepatitis B is a serious illness and as haemodialysis is a recognised risk for acquiring Hepatitis B vaccination is advised. The vaccination course varies, depending on the product used, but it is usually 3 or more injections, over a 6-month period, with a follow-up blood test to check if immunity has developed. Some people need an additional

- injection (boost) or a repeat course to develop immunity. In addition, people on haemodialysis or peritoneal dialysis have a blood test, yearly, and, depending on the result, may need a boost.
 - **Varicella** (chicken pox) - Vaccine for patients not immune and planning to receive a transplant.
- People should not get the vaccines if they ever had a life-threatening allergic reaction to yeast (Hepatitis B), eggs (flu) and/or to a previous dose (all vaccines). Pregnant women should discuss vaccination, with their doctor, and people who are ill should defer vaccination until feeling better.

While a vaccine, like all medicines, is capable of causing a serious problem, such as severe allergic reaction, the risk of vaccinations causing serious harm, or death is extremely small. **Getting vaccinations is much safer than getting the disease.**



Good handwashing practice is essential to avoid the spread of infections



WHAT CAN PATIENTS DO TO HELP REDUCE THE SPREAD OF INFECTIONS IN HOSPITALS?

Patients can help reduce the risk of all infections spreading by:

- Washing hands or using alcohol gel after using the toilet and before meals.
- Reminding staff to wash their hands, or use alcohol gel before they care for you.
- Advising visitors who are feeling unwell not to visit.
- Advising visitors to wash their hands before and after visiting and to avoid going from one ward to another during visiting time.
- Seeking advice from ward staff if young children wish to visit.
- Complaining to the ward sister/consultant or any staff member if the general ward hygiene is not satisfactory or if staff are not washing their hands.

PREVENTING THE SPREAD OF ALL INFECTIONS IN HOSPITALS

This hospital, along with all hospitals in the country, is working hard to reduce the spread of all infections in hospitals by:

- Improving hygiene throughout the hospital;
- Improving hand hygiene of staff and patients;
- Implementing antibiotic policies;
- Education of staff, patients and visitors;
- Increasing space between beds and number of single rooms especially as new wards are built.

CHAPTER 7

PRACTICAL AND SOCIAL SUPPORT

The Kidney Patient Care Co-ordinators, at Beaumont Hospital, will provide you with practical and social support and advice, will liaise with you and your family regarding any particular difficulties which your illness presents, and will advise you accordingly. This encompasses a wide range of topics, from the different treatment options to practical help with housing, medical cards etc.

Once you have been diagnosed with End Stage Kidney Disease (ESKD), you will be referred to one of the Patient Care Co-ordinators either through the ward, the out-patients department, or your Consultant. Your allocated co-ordinator will then provide information on education, support, practical advice and any other assistance possible to help you in the transition to kidney replacement therapy (RRT).

EDUCATION

The Patient Care Co-ordinators, in conjunction with other members of the kidney team, run education sessions from time to time. These are specifically aimed at patients who are approaching ESKD and aim to answer the many questions that you will have at this time. They include information on the different treatments available for kidney disease such as haemodialysis, peritoneal dialysis or transplantation, and explain the options available to you, at this time. If you are unable to attend one of these sessions or, if there is no session planned at the time of your diagnosis, the Patient Care Co-ordinator will provide all the necessary information on a one-to-one basis.

PRACTICAL ADVICE

When you or someone in your family is diagnosed with a chronic illness such as kidney disease, the resulting non-medical financial burden can further complicate the stress involved, and, it is important to become aware of the various assistance schemes available from the Department of Social Protection, the HSE and Local Authorities.

Not everyone is automatically entitled to financial assistance and some schemes are means tested. Specific individual circumstances are also taken into account; therefore, one person may qualify for assistance, while another, with the same illness, may not. You can only find out about your position by making an application and providing all the details required so that the relevant authority can determine your eligibility. Your Patient Care Co-ordinator can provide advice on your entitlements and, where applicable, provide a letter of support to accompany your application.

"Not everyone is automatically entitled to financial assistance, and some schemes are means tested."

The area of grants/allowances/benefits is a wide-ranging one that cannot be covered in detail in this publication. On the following pages is an overview of what financial assistance may be available and included at the end is a list of the relevant organisations to which you can apply for further information.

BENEFITS AND ENTITLEMENTS

There are three categories of eligibility for health services: medical card holders, GP visit card holders and non-medical card holders.

Medical card holders are entitled to free hospitalisation, GP services, most prescribed drugs and a range of other health services. A medical card is means tested, based on the applicant's weekly income less PRSI. There is a prescription charge with your medical card.

Further information and a medical card application form can be obtained from your local health centre or can be downloaded from **www.citizensinformation.ie**.

Hardship cases are dealt with on merit and special circumstances such as chronic illness can be taken into account. In cases of financial hardship, medical card holders may apply to their local HSE office for assistance with the cost of on-going prescribed medical items not available

under the Medical Card Scheme. If you feel you need a medical card, do apply for one. A supporting letter may be obtained from your attending hospital on request.

GP visit card holders are entitled to free visits to their GP. This card is issued based on specific income guidelines. In some cases, where a person may have a chronic illness which involves regular GP visits, the HSE may grant the GP visit card even where their income is greater than the guidelines. Largely, the HSE will only consider these applications where an ongoing medical condition is causing, or likely to cause, undue financial hardship.

Non-medical card holders are liable for a Government Levy for in-patient stays. Non-medical card holders can avail of the Drugs Payment Scheme through their local pharmacy. Under this scheme, families (patients, their partners and dependant children) pay a fixed amount per month for prescribed medicine.

TAX RELIEF ON MEDICAL EXPENSES

Medical expenses of the entire family qualify for tax relief. Further information is contained in Leaflet IT6, which is available from the Revenue Commissioner, tel. 1890-306706 or visit their website at **www.revenue.ie**.

Additional tax relief is available for kidney patients on expenditures such as travel, telephone and electricity.

For further information see pages 62-63.

DISABILITY ENTITLEMENTS

Patients who were employed, pre-dialysis, are fully encouraged to continue in their work/full-time education/training. However, there are cases where this is not an option and there is a range of entitlements to assist those who find themselves on a reduced income due to illness.

Illness Benefit is a short-term payment paid to insured people who are unfit for work due to illness.

You will qualify if you:

- are under 66;
- are unfit for work due to illness;
- satisfy the PRSI contribution conditions.

Invalidity Pension is a long-term payment. To qualify, you must be permanently incapable of working. You must satisfy both PRSI and medical conditions.

contd...

Kidney Disease – A Guide for Patients

Disability Allowance is a long-term weekly allowance paid to people with a disability aged between 16 and 66. Your disability must be expected to last for at least one year and the allowance is subject to both medical suitability, means test and habitual residency test.

Both Invalidity Pension and Disability Allowance entitle you to a free travel pass and you may qualify for a companion free pass if you are unfit to travel alone.

Working and Claiming a Disability Payment:

In certain circumstances, it may be possible to obtain a disability payment and work, provided the work is certified as being of a rehabilitative nature. People on Disability Allowance or Blind Persons' Pension may be allowed to retain their social welfare payment while working part-time (certain conditions apply). Written approval must be obtained from the Department of Social Protection. This may result in the withdrawal of a medical card.

Carer's Allowance is a payment for carers who look after a loved one in need of full-time care and attention. This payment is means-tested. If a carer looks after more than one person, they may also be eligible for an additional payment of 50%. A carer may work outside the home for a small number of

hours per week provided this has first been approved with the Department of Social Protection. Any money earned, however, will be assessed as means in deciding the amount of allowance due.

There are other allowances available with the Carer's Allowance such as:-

- Free travel pass
- Household benefit package
- A Respite Grant paid annually to all carers.

Carer's Benefit: Those who leave the workforce to care for a person in need of full-time care and attention may be entitled to Carer's Benefit, which is based on PRSI contribution.

If you already receive a Social Welfare Payment you are not eligible for Carer's Allowance or Carer Benefit. You may claim either, in place of your Social Welfare Payment.

"Carer's Allowance is a payment for carers who look after a loved one in need of full-time care and attention."

HEALTH SERVICE EXECUTIVE (HSE) PAYMENTS

Supplementary Welfare Allowance is an emergency payment for people without PRSI contributions. It is a basic minimum income to help bridge the gap while social welfare payments' applications are being processed. This payment is available from the local Community Welfare Officer and covers areas such as:

- Rent Allowance
- Mortgage Interest Payments
- Special Diet Allowance
- Heating Allowance.

Exceptional Needs Payment

Help towards expenses incurred during hospitalisation such as travel, clothing etc.

Other HSE payments include:-

- Mobility Allowance
- Respite Care Grant (as mentioned above)
- Blind Welfare Allowance
- Motorised Transport Grant
- Back-to-School Clothing and Footwear Allowance.

These payments can be obtained by applying to your local HSE with supporting documentation.

COMMUNITY WELFARE OFFICER (CWO)

Patients who need financial aid, outside of the Social Welfare system, may be entitled to assistance from the Community Welfare Officer (CWO), who is based at your local Health Centre. As a kidney patient, you may apply for various allowances such as Diet Supplement or Heating Allowance. Your Patient Care Co-ordinator will advise on the relevant allowances for you and will write to your local CWO to support your application as required.

For free information on your rights and entitlements contact:

CITIZENS INFORMATION

Tel: 0761-07 4000 (Monday to Friday, 9am to 8pm)

or **www.citizensinformation.ie**

for your local Citizens Information Centre.

LOCAL AUTHORITY GRANTS

The Housing Adaption Grant for people with a disability

This is a means tested grant to make a house suitable for a person with a disability. The grant can help you to make changes and adaptations to your home - for example, making it wheelchair accessible, extensions to create more space, adding ground floor bathroom or toilet or stair lift.

If you only require minor work you can apply for the Mobility Aids Grant Scheme. This is a means tested grant to provide mobility equipment, e.g. the installation of grab-rails, a level access shower or a stair lift.

The Housing Aid for Older Persons Scheme

This is a means-tested grant and is used to improve the condition of the older person's home. The type of work that is grant-aided includes structural repairs or improvements, rewiring repair or replacement of windows and doors, the provision of water, heating and sanitary services, cleaning and painting, or any other improvement work considered necessary.

Apply to the housing department, of your local authority, for each of these schemes. You may need an Occupational Therapist (OT) to assess your daily living needs in support of your application.

"Local community groups sometimes have funding to provide security aids, such as personal alarms, security lighting, mobility and safety aids."

SECURITY FOR THE ELDERLY

Local community groups sometimes have funding to provide security aids such as personal alarms, security lighting, mobility and safety aids. Your local Citizen's Advice Bureau might know if such schemes exist, in your area, or you can apply to the HSE Local Authority or the Gardai. Online and written information on all entitlements is available at **www.citizensinformation.ie**.

Kidney Disease

– A Guide for Patients

FOLLOWING DISCHARGE

The transition to kidney replacement therapy and/or transplantation is eased by the constant presence of medical and nursing staff while you remain in hospital. Once discharged, it is now time for you to adjust to this new way of life within the context of your own home and family life. There are many different ways that illness can affect your life. Maybe you are too unwell to do housework and need some home help. Perhaps you need meals-on-wheels. Whatever your requirements, your Patient Care Co-Ordinator will liaise with the relevant community services to ensure you have the appropriate support after your hospital stay.

PUBLIC HEALTH NURSE (PHN)

If you require any nursing care, following your discharge, you will be referred by the hospital to your Public Health Nurse, who is based in your local Health Centre. The Patient Care Co-Ordinator will ensure the PHN has all the necessary information required and will liaise with them with regard to your care.

HOME HELP SERVICE

Home help is available and works with vulnerable people in the community who, through illness or disability, are in need of help with day-to-day tasks.

A home helper might visit for a couple of hours, per day, to help with housework, shopping and might provide more personal care like help with washing, dressing or bathing.

Once you have been referred by the Patient Care Co-Ordinator or the Public Health Nurse, the local Home Help Organiser will assess you and approve the provision of a Home Help as appropriate.

MEALS-ON-WHEELS

These are organised on a voluntary basis and, again, a financial contribution



may be required. Your Patient Care Co-Ordinator or PHN will be able to ascertain if this service is available in your area and, if so, will make the necessary arrangements.

COMMUNITY REHABILITATION TEAM

The community rehabilitation team provides a home-led rehabilitation service for patients who meet the rehabilitation criteria.

The rehabilitation team consists of patients and their families, nurses, physiotherapists and occupational therapists. Patients can be referred to other services such as dietetics, chiropody, speech and language therapy, home help services and care agencies as required.

HSE LOCAL HEALTH OFFICES

Your local health office is your entry point to community health and personal social services. The wide range of services that are provided through local Health Offices and from Health Centres include general practitioner services, public health nursing, child health services, community welfare, chiropody, ophthalmic, speech therapy, social work, addiction counselling and treatment, physiotherapy, occupational therapy, psychiatric services and home help.

CHAPTER 8

REPRODUCTIVE MATTERS

SEXUAL ISSUES

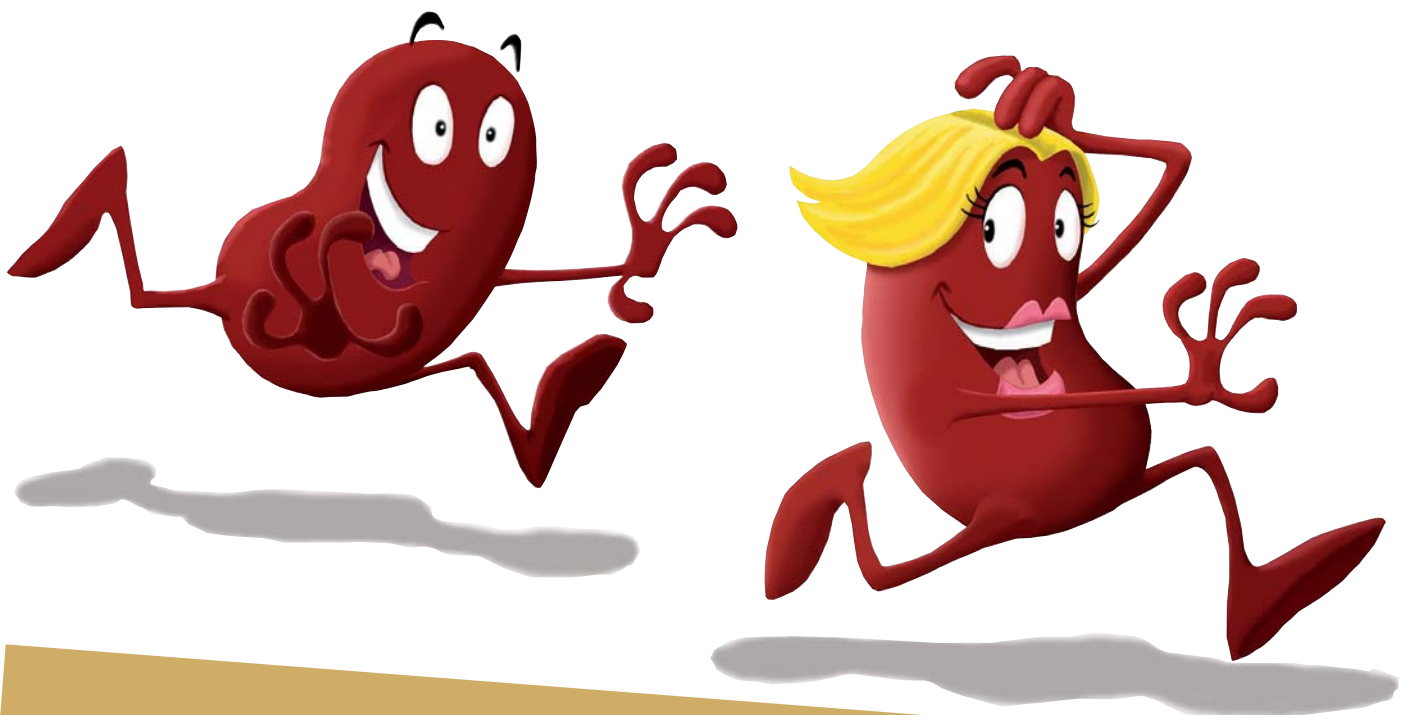
Sexual problems are common for men and women who suffer from kidney disease. Not only are emotional problems likely to occur as a result of the stress of the disease, but there are also a number of medical problems that can affect sexual function and fertility, both in men and women.

Emotional problems are common. Patients may find themselves going through a grieving process due to loss of kidney function, which may affect their independence, their job, and their role in the family. Some patients experience a change in body image. Dialysis can lead to lowered self-esteem, coupled with anger and depression, which can affect sexual function. The balance in the relationship may have changed - one seeing themselves as the carer and the other in a sick role. Couples need to communicate to one another their feelings and fears. Counselling can facilitate the exploration

of these feelings.

Contraception is important for people with kidney disease. Do not assume that because you have kidney disease, you cannot conceive a child. Most methods of contraception are suitable. Barrier methods such as condoms and diaphragms can be used. The coil can sometimes cause infection and heavy periods. The contraceptive pill has a tendency to raise blood pressure, sometimes one of the combined forms of oestrogen and progesterone are prescribed. The morning after pill may be used in the usual manner.

Fertility levels vary during different stages of kidney disease. Women of childbearing age do not often get pregnant while on kidney replacement therapy as the treatment only replaces a small percentage of kidney function, which, in turn, can interfere with egg production.



Kidney Disease

– A Guide for Patients

For female patients whose menstrual cycle remains, however irregular, it is possible to conceive. Although pregnancy is uncommon, some women have given birth. Due to risks to the mother and the high rate of miscarriage, patients are normally advised to take precautions against pregnancy. Some women decide to delay pregnancy for one or two years after they have had a kidney transplant.

"For female patients whose menstrual cycle remains, however irregular, it is possible to conceive."

Men with kidney disease may have a reduced sperm count and may experience difficulties in fathering a child. After successful transplantation, sperm numbers generally rise. Men with kidney disease can have a variety of sexual problems.

"Men with kidney disease may have a reduced sperm count and may experience difficulties in fathering a child."

These include loss of libido and ejaculatory problems.

However, the most worrying and most common is impotence. Impotence often has physical causes and is usually a combination of factors.

- Poor blood supply occurs as part of the natural ageing process and is common in older men. It is particularly common in men with diabetes and kidney disease.
- The testicles may produce less of the male hormone, testosterone.
- Some drug treatments can contribute to impotency, the biggest culprits being 'beta-blockers' such as atenolol, propranolol, metoprolol and bisoprolol.
- Tiredness can affect sexual performance. This can be caused by anaemia, under-dialysis or other medical problems e.g., heart problems.
- Psychological or relationship issues.

Treatment for impotence is commenced by checking out general health. Anaemia, if present, is corrected, treatment time may need to be extended

or drug treatment may be changed.

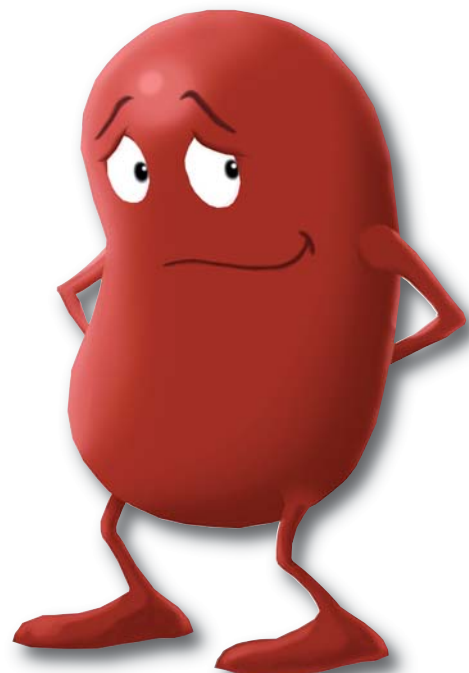
Viagra is commonly prescribed. Trials show that about 8 out of 10 men benefit with improvement in erectile performance. Patients with angina or heart problems should not take Viagra. It is advisable to consult your unit doctor to ensure that it is a safe option in your case.

There are many other interventions which are performed by specialist doctors e.g., urologists. A referral is sent from the unit doctor.

Counselling is recommended for emotional problems relating to impotence.

Many men, who have had difficulty fathering a child while undergoing kidney replacement therapy, have been successful in doing so following transplantation.

Communication is the most important factor in any relationship. Wherever there is a problem share your feelings and fears with your partner. Nursing and medical staff recognise that patients can have difficulties in sexual relationships and will gladly talk to you and your partner. Professional guidance can help - all that may be needed is a little reassurance.



CHAPTER 9

YOUR KIDNEY HEALTHCARE TEAM

Your kidney health care team has many years of experience treating people with kidney disease. If you have a question or are looking for information, ask any member of your healthcare team. If they can't help, they will refer you to someone who can. Do not hesitate to ask.

Because your kidney healthcare team is important to you, we describe, in this chapter, the roles and skills of each team member. This may help you to decide which people it may be beneficial to consult.



*Professor
Peter Conlon*



Dr. Magee

NEPHROLOGIST

A Nephrologist (or Consultant) is a doctor who specialises in kidney disease and who, together with you and the other members of the healthcare team, plans the best treatment for you.



Dr. Mark Denton



Dr Conal O'Sheaghda



*Dr. Declan
De Freitas*

Kidney Disease

– A Guide for Patients

The Nephrologist in a teaching hospital will typically have a team of non-consultant hospital doctors assisting them in your care. These doctors include the following:



Professor Peter Conlon (left) and his team

RENAL REGISTRAR

A renal registrar will have completed at least 3 years of post-graduate medical education. They will be responsible for the supervision of the Senior House Officers and Interns. A registrar will typically be participating in a 4 to 5 year training programme on kidney diseases.

SENIOR HOUSE OFFICER

The senior house officer will be at least 1 year post-graduation from medical school and is training in the general aspects of hospital medicine.

INTERN

In the first year after graduation from medical school, all medical students must spend a year of training in the hospital to learn the fundamentals of hospital medicine

MEDICAL STUDENTS

Training hospitals will have many medical students. These students will talk to you about how the disease has affected you. They will also ask for permission to examine you. This is how they become a doctor themselves one day. On ward rounds frequently the Registrar or Consultant will ask the medical student to present their findings about you and your condition to the team. It is your choice to specify that you do not wish to see medical students if you are not feeling up to it.



*Sr. Maureen McNulty, CNM2
St. Peter's Ward*

NEPHROLOGY NURSE

Nephrology nurses work closely with you, your family and other team members. They will teach you and your family about your kidney disease and its treatment, and support you in the lifestyle changes that you may need to make. In some units,

Clinical Nurse Specialists, Nurse Clinicians or Nurse Practitioners may also be part of the team. On each ward, a Clinical Nurse Manager will be responsible for the day-to-day management of the unit.



*Petrina Donnelly, CNM
and Mary Joseph*



Margaret Hanna, Renal Nurse Counsellor

RENAL NURSE COUNSELLOR

Many kidney units in Ireland have access to a Counsellor who has specific experience in looking after patients with chronic kidney disease. Being diagnosed with kidney disease can be very difficult for you, your partner and your family. The Renal Counsellor will work closely with you and your family to help adjust to this new lifestyle.

STUDENT NURSES

Currently it takes four years at university to become a registered nurse. Student nurses spend much of this time rotating in different areas within the hospital. Student nurses will have different levels of experience, according to what year they are studying in university.

DIETICIAN

The dietician will instruct you on the proper food choices you may need to make as part of your treatment. Following consultation with your doctor and yourself, the dietician will then prepare a daily eating plan.



*Olive McEnroe, Ruth O'Malley and Louise McSkeane
Ambulatory Care Nurses*

AMBULATORY CARE

You will meet the Ambulatory Care Nurses in the out-patient department. They will provide you with education and support and will make referrals to other members of the team, on your behalf. They will also co-ordinate the necessary tests if you are deemed suitable for a transplant.

PATIENT CARE CO-ORDINATOR (PCC)

Your Patient Care Co-Ordinator is available to provide supportive counselling to you and your family. You may benefit from discussing emotional, financial, family or other concerns with your Patient Care Co-Ordinator as you try to understand and adjust to the changes that result from having kidney disease. They can also assist you with information about community resources and financial aid programs.



*Mary T. Murphy, Eileen McBrearthy and Angela Bagnell,
Patient Care Co-ordinators*

Kidney Disease

– A Guide for Patients



Mr. David Hickey, Transplant Surgeon

SURGEON

A surgeon is a doctor specifically trained in surgery. A surgeon will perform the operation to establish access for dialysis, or to transplant a kidney.



YOUR FAMILY DOCTOR (GP)

It is important that you continue to visit your family doctor. He, or she, knows you and your family best. Your kidney healthcare team will take excellent care of any problem associated with your kidney disease. However, your family doctor is best suited to provide preventative healthcare check-ups, such as pap smears and prostate examinations, and to look after any other healthcare needs. The kidney healthcare team will communicate with your GP on a regular basis.



TRANSPLANT CO-ORDINATOR

The role of the co-ordinator is to serve as recipient co-ordinator for people awaiting kidney transplant. They facilitate and co-ordinate live kidney donation as well as co-ordinating donor referrals.

TRANSPLANT CO-ORDINATORS

(L-R): Regina Reynolds, Laura Donovan, Phyllis Cunningham and Andrea Fitzmaurice. Missing from photo: Aileen Counihan

CARE ATTENDANTS

Work closely with nursing staff in providing your nursing care.

PHARMACIST

Works closely with members of the kidney healthcare team. They provide you with information, surrounding your medications, to ensure you have full understanding of your treatment.

HOUSEHOLD OPERATIVES

Responsible for household activities at ward level. They assist with stocking of equipment and supplies.

PORTERING STAFF

Assist by transporting patients to, and from procedures.

WARD CLERKS

Will ensure that the correct information is gathered in relation to:

- Medical Card Number
- Health Cover

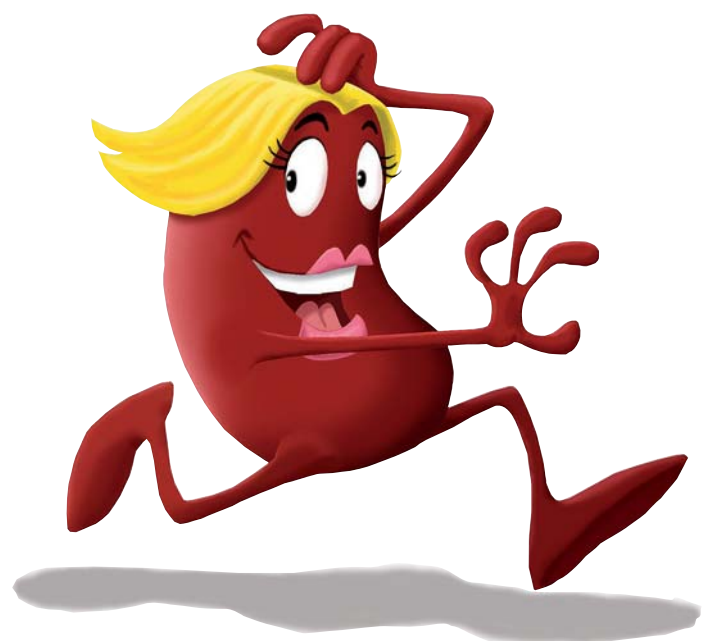


DOMESTIC STAFF

Responsible for ward cleaning to ensure hygiene standards are maintained.

CATERING STAFF

Ensure that the food you receive is of a high standard. Also, they will order any special diets that your dietician has ordered for you.



CHAPTER 10

STAYING HEALTHY



Taking part in pleasant leisure activities and maintaining a well-balanced lifestyle can go a long way toward helping you stay healthy. And have fun! It is important to take part in social activities, sports and recreation events, and other pastimes that you, and other members of your family and friends enjoy. You may need to make a few adjustments, but they will be well worth it.



EXERCISE AND SPORTS

Exercise is vitally important to both your physical and mental health. Staying physically fit will give you more energy. With more energy, you will feel like doing more things which will improve your outlook and speed your return to your usual lifestyle. Talk to your healthcare team about a suitable exercise or sports program before you begin (or resume) these activities.



There are many benefits to be enjoyed from exercise and these include:

- Improved physical functioning
- Better blood pressure
- Improved muscle strength
- Lower level of blood fats
- Better sleep
- Better control of body weight
- Reduced risk of heart disease
- Development of stronger bones
- Reduced stress and depression
- Meeting people
- Having fun.

If you are interested in getting and staying fit, then remember the **F.I.T.T** principle. Studies have shown that for it to be effective you must exercise:

- **F**requently
- Reach a minimum **I**ntensity
- Continue for a minimum length of **T**ime
- Do an appropriate **T**ype of exercise



Frequency

To ensure that you get a positive effect, exercise at least three times a week. Unless you exercise this often, your physical conditioning will not improve. Spread the exercise over the week. Do not do it all on consecutive days. This gives your body time to recover and build up your muscles and energy for the next time.

Intensity

Unless you exercise hard enough, you are not going to get much benefit from it. There are different ways to measure intensity. One of the most common is by measuring your heart rate as you exercise. Talk to your doctor or someone who specialises in physical conditioning.

Kidney Disease

– A Guide for Patients

Time

The exercise must last at least 15 minutes to be effective. Any less, and your physical conditioning will not change. If you're not able to exercise continuously for that long, try doing it a little less vigorously, or pause for a couple of minutes to catch your breath, then keep going. The longer you keep it up, the more good it will do you.

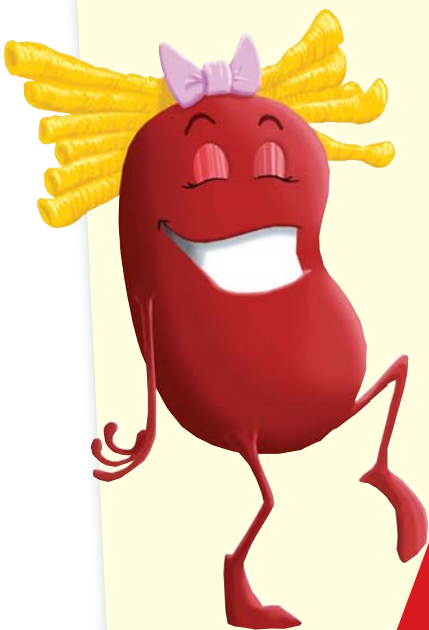
Type

Some exercises are better than others. Some of the best are walking, swimming, and riding a bicycle. They get most of your muscles working and increase your heart rate to a healthy level. You can also adjust the intensity to suit your level of fitness. Best of all, they're fun to do.

Before you start a vigorous exercise program, check with your healthcare team—they can advise you on which exercises are best for you, and which ones, if any, you should avoid.



GENERAL HEALTH ADVICE



NUTRITION

Eat a healthy diet, this means eating a wide variety of foods, in the correct amounts, to ensure good health. *Important points:*

- Eat three main meals a day.
- Avoid fried and fatty foods.
- Eat more fruit and vegetables.
- Eat more fibre rich foods.
- Reduce sugary foods and sweetened drinks.
- Avoid adding salt to foods.
- Adhere to diet restrictions such as low salt, low cholesterol and diabetic diets according to doctors' or dieticians' instructions.
- Fluid restrictions may be necessary to maintain, please follow your doctor's advice regarding same.

WEIGHT CONTROL/EXERCISE

Exercise has a positive affect on blood pressure, cholesterol levels and the functioning of the heart and lungs even if you do not lose weight.

Adopt a regular exercise pattern if one does not exist in your life. This is essential to maintain a healthy body weight and decrease the risk of obesity.

CLINIC APPOINTMENTS

Please attend all Out-Patient or other clinic appointments to ensure a continuous record of medical history. If you are unable to attend any scheduled appointments, please inform the department for further available dates.

"Please keep a list of all current medications with you on all health visits as it is important to have an up-to-date record."

MEDICATIONS

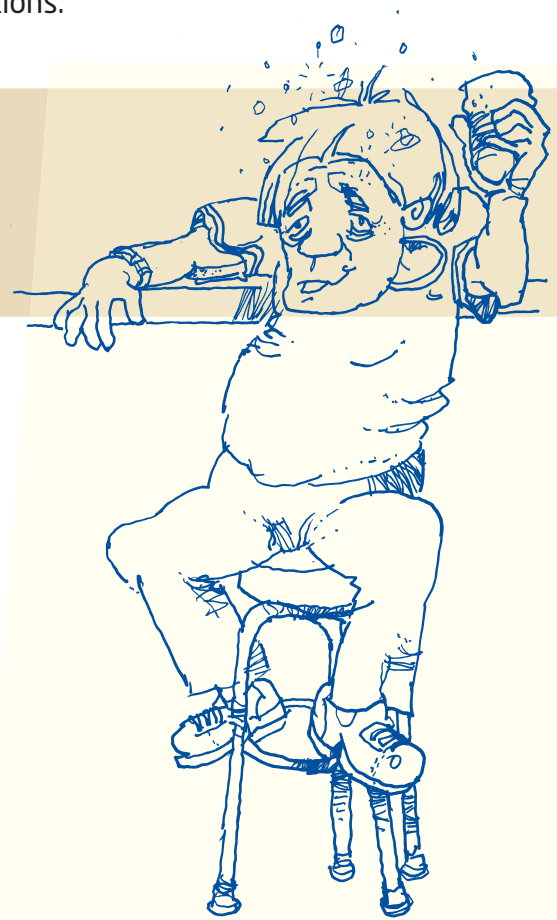
Please keep a list of your current medications with you on all health visits, as it is important to have an up-to-date record. Medications, not prescribed by your doctor, should not be taken.

Avoid herbal remedies without seeking medical advice, as some may interact with specific medications.

STRESS

Decreasing stress will improve your psychological health, which is essential to general health and well-being.

Further help may be sought from the kidney nurse counsellor or therapist.



SMOKING AND DRUGS

If you are currently smoking, try firstly to cut back and, over a period of time, to cease.

Smoking damages the lungs and puts you at risk of lung cancer.

Smoking tobacco, marijuana or other drug use is harmful to everyone.

Any form of 'recreational drugs', such as ecstasy, speed or cocaine, can have a serious effect on your body and mind.

These drugs may also interact with your medications.



"Any form of 'recreational drugs' such as ecstasy, speed or cocaine can have a serious effect on your body and mind."

ALCOHOL INTAKE

Alcohol is high in sugars and calories. Excess alcohol can increase your triglyceride level and promote weight gain.

Use sugar free mixers such as diet minerals or slimline tonic.

Have 2-3 alcohol free days per week and, when taking alcohol, do not exceed the recommended limits:

(A) **Men:** 21 units per week.

(B) **Women:** 14 units per week.

Kidney Disease – A Guide for Patients

The Irish Kidney Association Renal Support Centre is located in the grounds of Beaumont Hospital, just 100 metres walk from the main hospital entrance, is open all year round and provides free accommodation for all its residents, who include:



- Families of renal patients from outside Dublin. It is available to all renal families no matter what Dublin hospital their family member is attending.
- Renal patients who have to travel long distances to see their consultant as an outpatient may stay overnight when accommodation is available.
- The Centre arranges counselling service as required by outpatients and their families. The counselling service is located at Donor House.

- Preference for accommodation is given to families of patients receiving transplants and families of the seriously ill.

FACILITIES

Twelve en-suite bedrooms some of which can sleep up to four persons. All rooms are on ground floor level. All rooms have satellite TV, hairdryer, refrigerator and ironing facilities. There is direct contact with the hospital ward. Comfortable sittingroom/dayroom with satellite TV. Fully fitted kitchen where meals can be prepared by residents. Complimentary tea and coffee is provided by the Association for residents and guests. Soft drinks and snacks available from vending machine. Laundry room with washing powder supplied. Parking for overnight residents only.

The Centre is owned and funded by the Irish Kidney Association. Donations from residents and fundraising initiatives are most welcome.

The Centre is open to residents all year round. Day facilities are available Monday to Friday from 8.30am to 4.30pm, Saturday and Sunday 12pm-4pm.



For further information contact:

IKA Renal Support Centre, Beaumont Hospital, Dublin 9.
Telephone: 353-1-837 3952. Out of hours (Emergency only): **087-416 9907**
Email: renalcentre@ika.ie

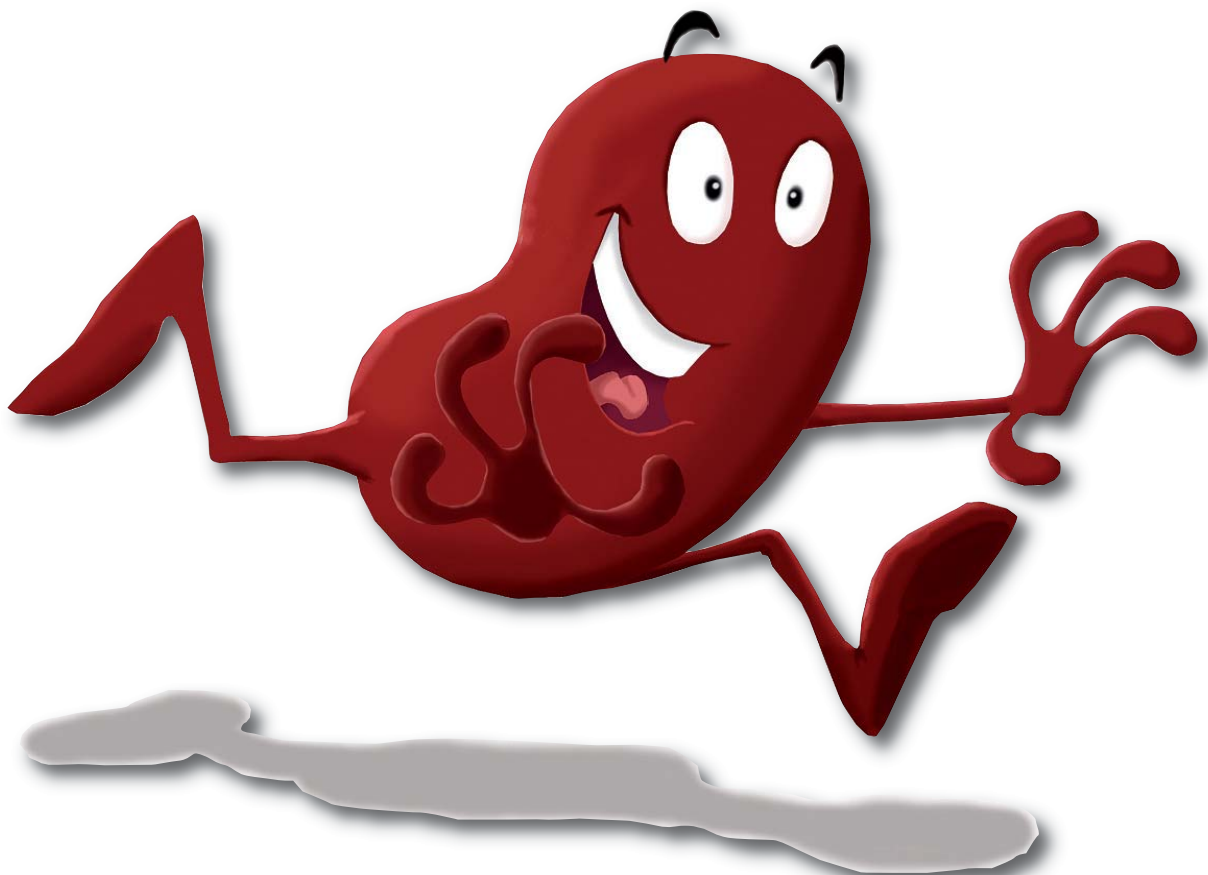
GLOSSARY

TERM	DEFINITION
AKD - Acute kidney disease <i>ALSO CALLED</i> AKI Acute kidney injury	A sudden loss of kidney function that is often reversible.
AVF - Arteriovenous fistula	Vascular access for dialysis; joining an artery and vein together.
Anaemia	A shortage of red blood cells in the blood. One of the functions of the kidneys includes EPO (erythropoietin) production. When the kidneys fail, EPO is not made leading to anaemia.
ANCA - (Anti-neutrophil cytoplasmic antibody)	A type of antibody that is associated with vasculitis conditions.
APD - Automated peritoneal dialysis	Also known as CCPD. This is a form of peritoneal dialysis which is carried out overnight.
Arteries	Blood vessels that carry blood from the heart to the rest of the body.
Blood Tests	A blood test that is used to measure many substances in the body to ensure they are within normal/safe range.
Blood Pressure (B/P)	The pressure that the blood exerts against the walls of the arteries as it flows through them.
CAPD - Continuous ambulatory peritoneal dialysis	Infusion of fluid into the peritoneum, prolonged dwell period and then drainage.
Central Venous Catheter (CVC)	Also known as permcath. A catheter with two ports inserted into a major central vein for the purpose of haemodialysis.
Creatinine	A waste substance produced by the muscles when they are used. The higher the blood creatinine level, the greater the indication of kidney disease.
Chronic kidney disease (CRF)	Slow onset of kidney disease which is irreversible.
Dehydration	Not sufficient water in the body to maintain normal function.
Dialysis (HD)	An artificial process which removes chemical substances and water from the blood by passing it through an artificial kidney.
End Stage Kidney Disease (ESKD)	Advanced kidney disease.
Erythropoietin (EPO)	Hormone involved in production of Red Blood Cells.
Fluid Overload	The body contains excess water. This occurs in kidney disease as one of the functions of the kidney is to remove excess waste.

Kidney Disease – A Guide for Patients

GLOSSARY

TERM	DEFINITION
Haematuria	Blood in the urine.
Hepatitis	An infection of the liver. Can be passed on by blood contact.
Kidneys	Two bean-shaped body organs where urine is produced. Functions of the kidney include removal of toxic waste, removal of excess fluid, controls blood pressure, helps to produce red blood cells and helps to keep bones strong and healthy.
Nephron	Small filtering unit in the kidney, made up of blood vessels and tubules.
Oedema	A build up of fluid causing swelling, especially ankles and the lungs.
Oliguric	Passing low levels of urine.
Potassium	A mineral that is normally present in the blood. Too much or too little can cause complications.
Transplantation	The replacement of an organ that is not working in the body with another donor organ.





Contact Numbers

Beaumont Hospital	01-809 3000
St Peter's Ward	01-809 2285/2290
St Damien's Nephrology	01-809 2323/2324
St Damien's Urology	01-809 2292/2293
St Theresa's Ward	01-809 2294
Renal Day Care	01-809 3144
Patient Care Co-Ordinators	01-809 2727
Renal Nurse Counsellor	01-809 3931
Ambulatory Nurse Specialist	01-852 8395
Prof Conlon's Secretary	01-809 2747
Dr Magee's Secretary	01-797 4701
Dr Denton's Secretary	01-809 3080
Dr de Freitas Secretary	01-809 3357
Dr. O'Seaghdha's Secretary	01-809 2567
Transplant Co-Ordinators	01-809 3119
Home Therapies	01-852 8152

Useful Information Websites

BEAUMONT RENAL UNIT - www.beaumontkidneycentre.ie

IRISH KIDNEY ASSOCIATION - www.ika.ie

IRISH HEALTH WEBSITE - www.irishhealth.com

AMERICAN ASSOCIATION OF KIDNEY PATIENTS - www.aakp.org

NATIONAL KIDNEY FOUNDATION USA - www.kidney.org

Kidney Dialysis Centres

Beaumont Hospital, Dublin

Tel: 01-809 3000

**Beacon Renal,
Sandyford, Dublin**

Tel: 01-299 8100

Cavan General Hospital

Tel: 049-437 6032

Cork University Hospital

Tel: 021-492 0883

Daisyhill Hospital, Newry

Tel: 028-3083 5035

Fresenius Kilkenny

Tel: 056-777 2751

**Fresenius Dock Road
Limerick**

Tel: 061-498 040

**Fresenius Northern Cross
Dublin**

Tel: 01-866 1314

Letterkenny General Hospital

Tel: 074-912 3544

Limerick Regional Hospital

Tel: 061-482 377/482 400

**Mater Misericordiae Hospital,
Dublin**

Tel: 01-803 2400/803 2405

Mayo General Hospital

Tel: 094-904 2414

Merlin Park Hospital, Galway

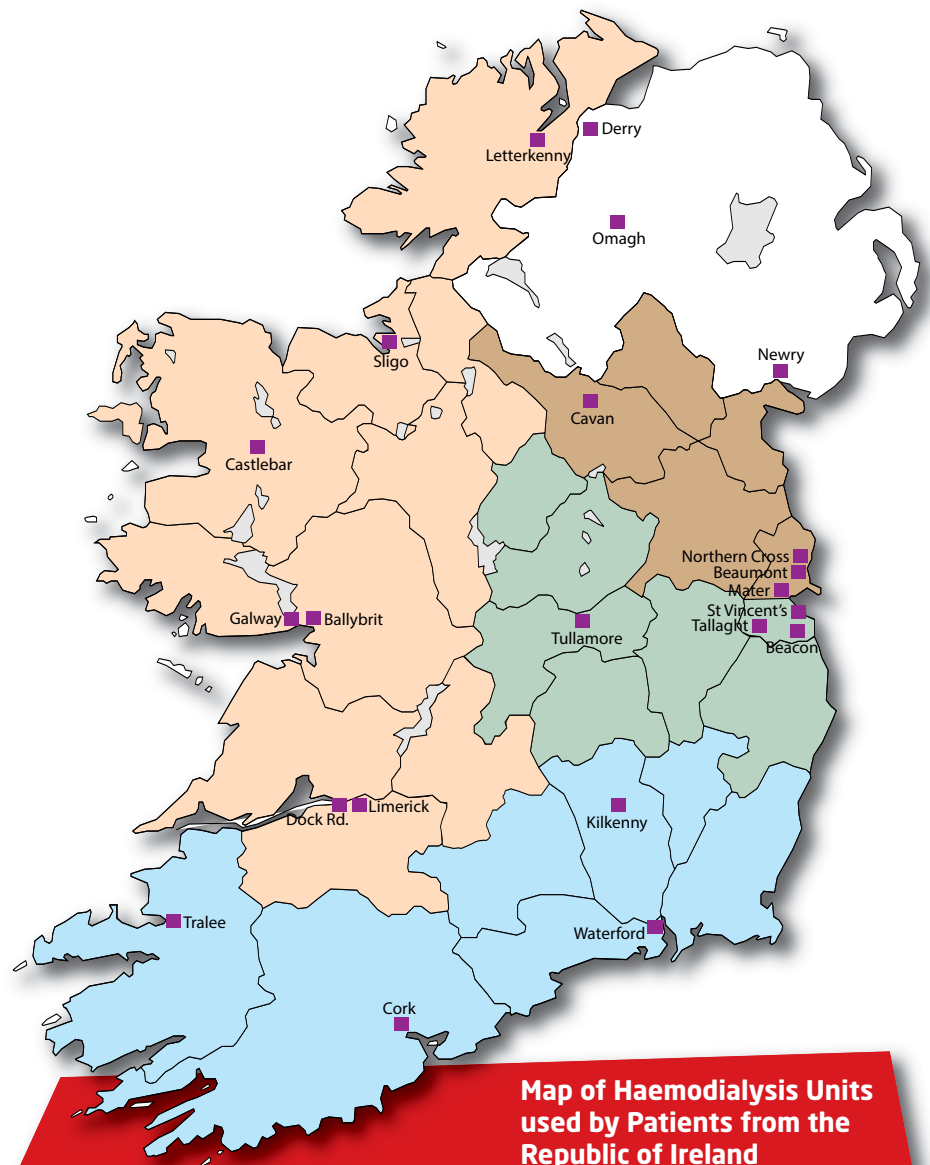
Tel: 091-775 575/775 574

**Our Lady's Children's
Hospital, Crumlin, Dublin**

Tel: 01-409 6029/409 6948

Sligo General Hospital

Tel: 071-917 4598



**Map of Haemodialysis Units
used by Patients from the
Republic of Ireland**

**St. Vincents University
Hospital, Dublin**

Tel: 01-277 4427/277 3089

Tallaght Hospital, Dublin

Tel: 01-414 2358/414 2350

**Temple Street Children's
Hospital, Dublin**

Tel: 01-878 4757

Tralee General Hospital

Tel: 066-718 4330

Tullamore Regional Hospital

Tel: 057-935 8733

Waterford Regional Hospital

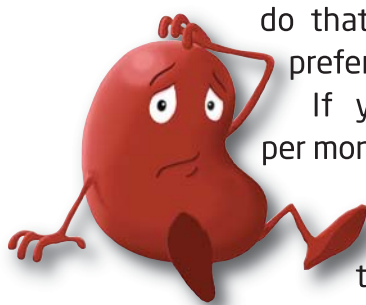
Tel: 051-842 753

Wellstone Ballybrit, Galway

Tel: 01-709 1844

Tax relief on health expenses incurred by kidney patients

All patients that pay tax are encouraged to complete a Revenue form Med 1 health expenses claim for relief which will relieve the financial burden somewhat at the standard rate of tax. The form can be downloaded from the revenue website, or we can do that for you if you would prefer.



If you are paying €144 per month for your medications for the whole year of 2013 you will be able to claim €1,728.00 on your Med 1 form at 20% standard rate you will be due a €345.60 tax refund. You can make a claim for the previous 3 years also. In 2012 the Drug Payment Scheme limit was €132.00 and €120.00 for 2011.

If, as an individual patient you are not working and do not pay tax, but your spouse is working and paying tax they can make the Med 1 claim for a refund on their taxes.

A person on haemodialysis in a hospital or clinic, who does not avail of a HSE means of transport and who pays tax may make a claim for their travel expenses.

A. Hospital dialysis patients (where the patient attends hospital for treatment)

Relief in respect of expenditure incurred travelling to and from hospital (unlimited journeys for all years) may be allowed at the following rates -

Mileage/Kilometric Rates

2009	€0.27 per mile or €0.17 per km
2010	€0.27 per mile or €0.17 per km
2011	€0.27 per mile or €0.17 per km
2012	€0.27 per mile or €0.17 per km

EXAMPLE 2 - YEAR 2012

Say you live 10 miles from your dialysis centre, typically you will travel 20 miles on your dialysis day and receive 156 treatments a year.

That is 3120 miles you can claim for @ 27 cent per mile
 = **€842.40** @ 20% tax rate = **€168.48 tax refund**
 - small but why not claim anyway?

Kidney Disease – A Guide for Patients

B. Home dialysis patients (where the patient uses a dialysis machine at home).

Relief may be allowed in respect of expenditure up to the following amounts –

Reliefs allowed

	2009	2010	2011	2012
Electricity	€1,665	€1,665	€1,910	€1,935
Laundry & protective clothing	€1,940	€1,925	€1,985	€1,960
Telephone	€301	€300	€310	€305
Travelling	€0.27 per mile or €0.17 per km	€0.27 per mile or €0.17 per km	€0.27 per mile or €0.17 per km	€0.27 per mile or €0.17 per km

EXAMPLE 2 - YEAR 2012

Presuming you are on dialysis for a complete calendar year 2012

Electricity	€1935.00
Laundry and Protective Clothing	€1960.00
Telephone	€305.00

Have 12 trips a year to hospital

20 miles return journey 240 miles @ 27 cent €64.80

Total Claim €4264.80 @ 20% = **€852.96 Refund**

C. Chronic Ambulatory Peritoneal Dialysis (CAPD) patients (where the patient has treatment at home without the use of a dialysis machine)

Relief may be allowed in respect of expenditure incurred up to the following amounts –

Reliefs allowed

	2009	2010	2011	2012
Electricity	€1,315	€1,315	€1,508	€1,530
Telephone	€301	€300	€310	€305
Travelling	€0.27 per mile or €0.17 per km	€0.27 per mile or €0.17 per km	€0.27 per mile or €0.17 per km	€0.27 per mile or €0.17 per km

EXAMPLE 3- YEAR 2012

Presuming as example above on for year 2012

Electricity	€1530.00
Telephone	€305.00
Travel (same as above example)	€64.80

€1899.80 @ 20% = **€379.96 Refund**

You make the claims above on the MED 1 FORM, page 2 at (J) – OTHER QUALIFYING EXPENSES.

Note: It is possible for a patient to move from one category of treatment to another. Where this happens, relief for each category may be apportioned as appropriate.

A tax refund cannot be more than the tax you have already paid in the given year. You can claim for 4 years. So in January 2014 you can only make a claim going back to 2010.

CONTRIBUTORS

*We would like to extend special thanks
to the following members of
the Renal Team at Beaumont
for their contribution to this book.*

Prof. Peter J. Conlon
Helen Dunne
Petrina Donnelly
Dr. Colm Magee
Dr. Mark Denton
Dr. Frank O'Brien
Dr. Claire Kennedy
Louise Kelly
Oonagh Deeney
Bernice Curtis
Margaret Hanna
M.T. Murphy
Eileen McBrearty
Dr. Darren Pachaippan
Martin Ferguson
Sheila Donlon

Cartoons and Illustrations

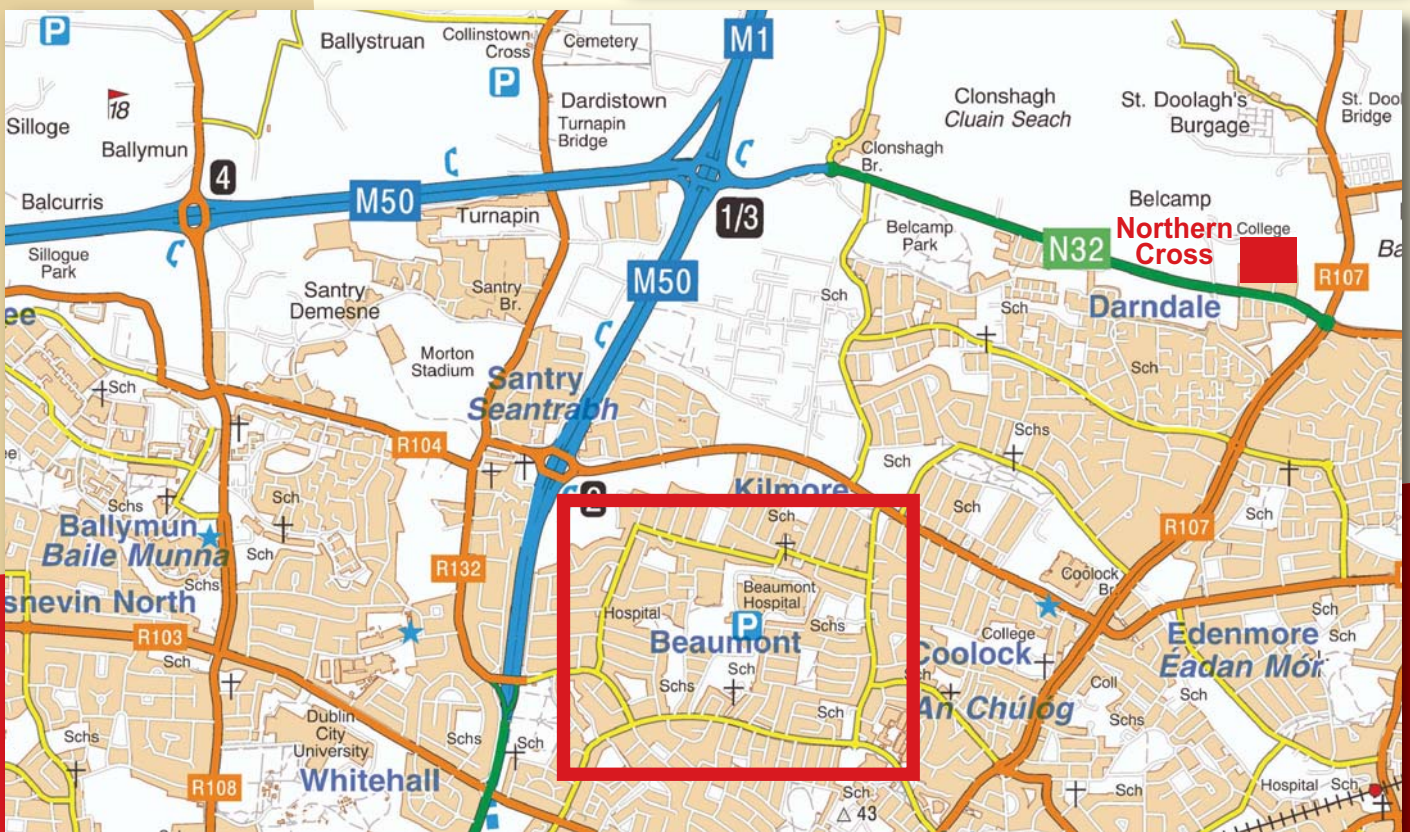
Des Hickey (deceased), **KegKartoonz** (Noel Kelly),
Jazz Communications Ltd., and **www.netterimages.com**

*Also, to the patients and staff who took time
to contribute to editing this book.*

Beaumont Hospital



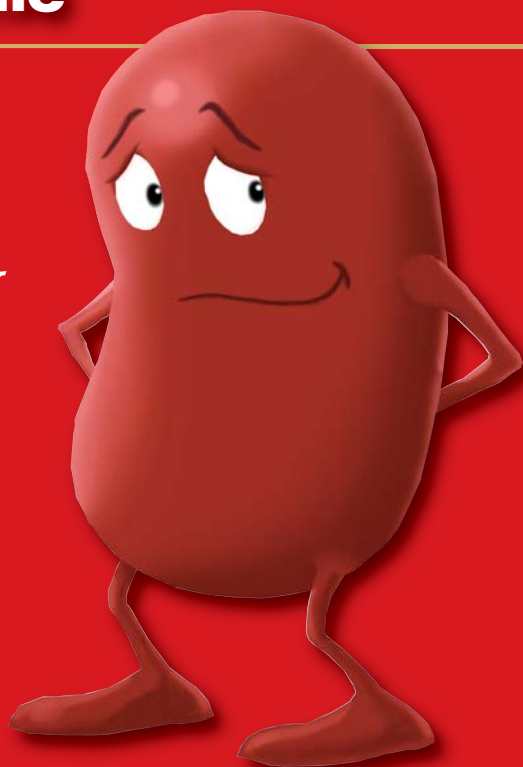
Beaumont Hospital
Beaumont Road, Dublin 9
www.beaumont.ie



www.beaumontkidneycentre.ie



Beaumont
**TRANSPLANT
FOUNDATION**



IRISH KIDNEY ASSOCIATION

Donor House, Block 43A

Park West, Dublin 12

Tel: 01-6205306

Lo-Call: 1890-543639 (1890-KIDNEY)

Email: info@ika.ie

Web: www.ika.ie