

IRISH KIDNEY ASSOCIATION

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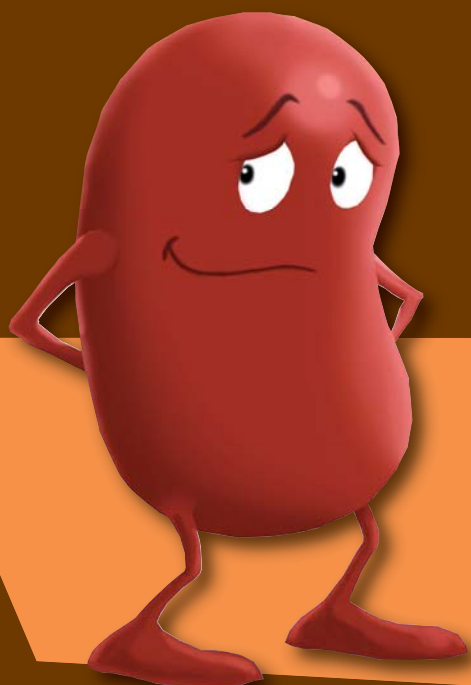


Living with

CHRONIC KIDNEY DISEASE

A Guide for Patients

BOOK 5



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IRISH KIDNEY ASSOCIATION (CLG)

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

The Irish Kidney Association Head Office is located in the west of Dublin, named 'Donor House'. The office is the main administrative and services centre for the Association. The staff is made up of Chief Executive, Accountant, Patient Support Office, Office Manager and Personal Assistant to CE, National Projects Manager, Renal Counsellor, Dialysis Holiday Co-ordinator, Receptionist, IT Developer, Social Media Co-ordinator and the Support Centre Managers. Individual names and email addresses for the staff are available on the IKA website.



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.

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PREFACE

This is the fifth book in a series of seven, aimed at helping patients with kidney disease learn more about their illness. This book (**BOOK 5**) 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)*. CKD is a term that is used by doctors to describe a reduction in kidney function from diseases such as hypertension and diabetes which can affect a person's health.

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; **BOOK 4** addresses the area of the 'living donor' programme; **BOOK 6** - Emotional Wellbeing and **BOOK 7** - deals with the Conservative Care of Kidney Failure.



CKD is generally a silent disease, that is for the most part, many patients will experience few if any symptoms. Kidney function can deteriorate gradually over time and some people can progress to kidney failure at which time a patient may require dialysis treatment and/or a kidney transplant. Early detection and treatment of kidney disease can often prevent it from getting worse. Good management of your kidney disease, by your General Practitioner (GP) and your kidney specialist (Nephrologist), will help prevent complications and protect your kidneys from deteriorating.

This book will help you understand more about CKD, how to diagnose it, its complications, and who is at risk. It will explain the benefits of early intervention and inform you of practical things you can do that will help look after your kidneys. Knowing more about your condition can help you to protect your remaining kidney function and overall general health.

You will read about steps you can take that are beneficial for your overall health and how you can come to terms with this diagnosis. The book also explains what will happen when and if your kidneys start to fail.

Whilst this book is primarily written for people with CKD, it is a useful resource for the people around you who want to find out more. Family and friends will be able to support you better if they understand more about your health condition.

If you have been diagnosed with CKD, do not ignore it because you do not have physical symptoms or because your kidneys are not failing right now. Take action to look after your kidneys so that you can preserve their remaining function as long as possible and live a healthy life.

ACKNOWLEDGEMENTS

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The information contained within this book is correct at time of going to press. This book should be used as a guide and reference tool only - always speak to your doctor if you have individual concerns.

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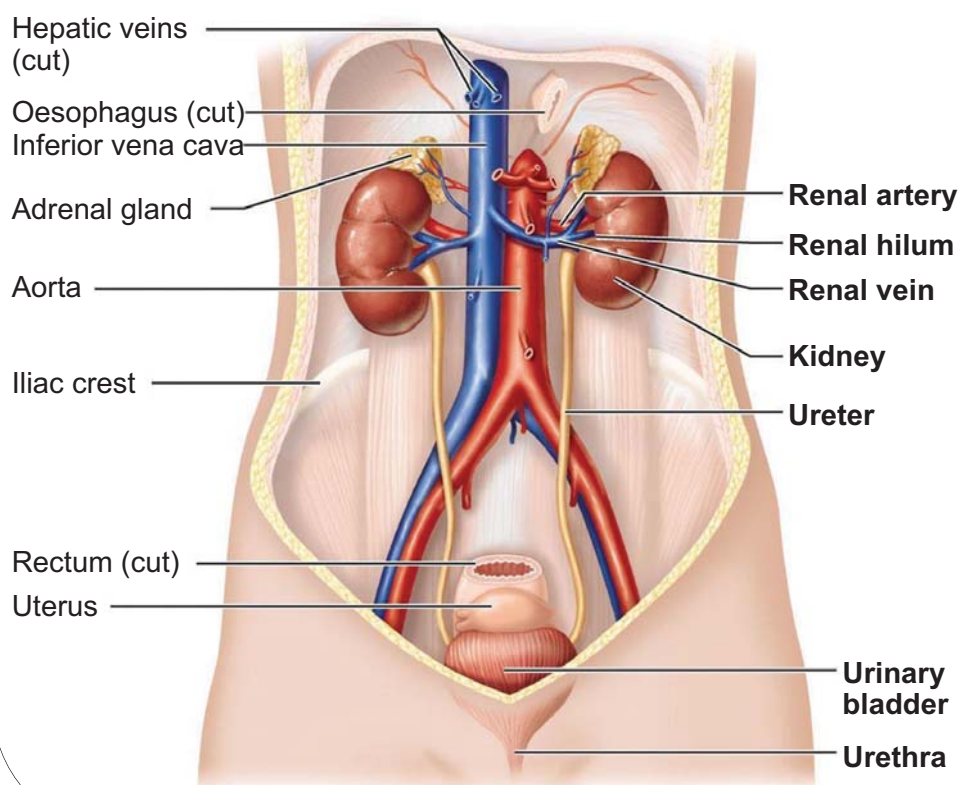
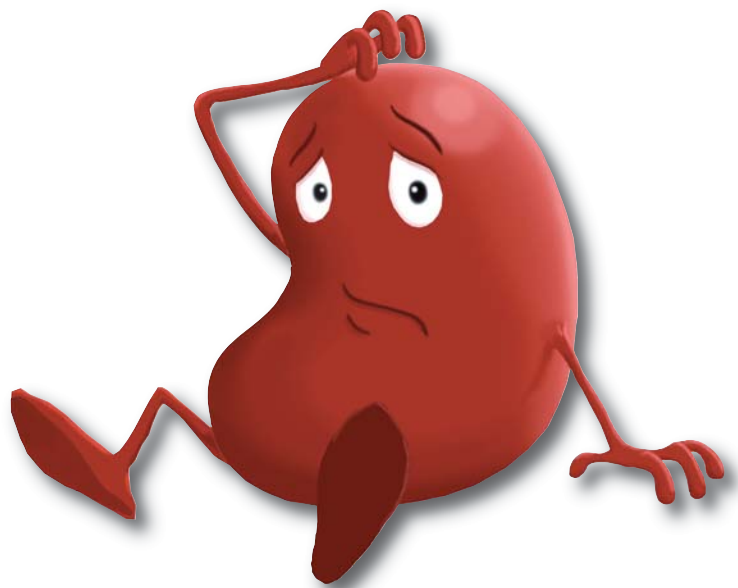
CHAPTER 1

WHAT ARE THE KIDNEYS AND WHAT DO THEY DO?

Before we get into what CKD is, it is useful to explain exactly what role the kidneys have in the body.

The two kidneys lie behind the other major organs in the lower back area. They are bean-shaped and measure about 11cm long by 6cm wide (the size of a clenched fist) by the time we reach adulthood.

Kidneys are basically a machine that filters your blood. As blood flows around the body, it collects 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 foods you eat.



Your body takes what it needs from the blood and then the waste needs to be removed from the body. The kidneys filter the blood and remove the waste products and excess fluids from the body in the form of urine, via the bladder.

The clean blood flows back to the other parts of the body. If your kidneys do not remove this waste, it builds up in the blood and causes damage to your body and ultimately may lead to death, if untreated.

The kidneys do an incredible job - it is estimated that one litre of blood enters the kidneys through the renal arteries every single minute. This blood is cleaned and then flows back, through the renal veins into the body.

The actual filtering process occurs in one of the many tiny units in the kidney called nephrons. There are around a million nephrons in each kidney and they carry out a complicated chemical exchange so that waste materials and water, in your blood, are separated out for the urinary system.

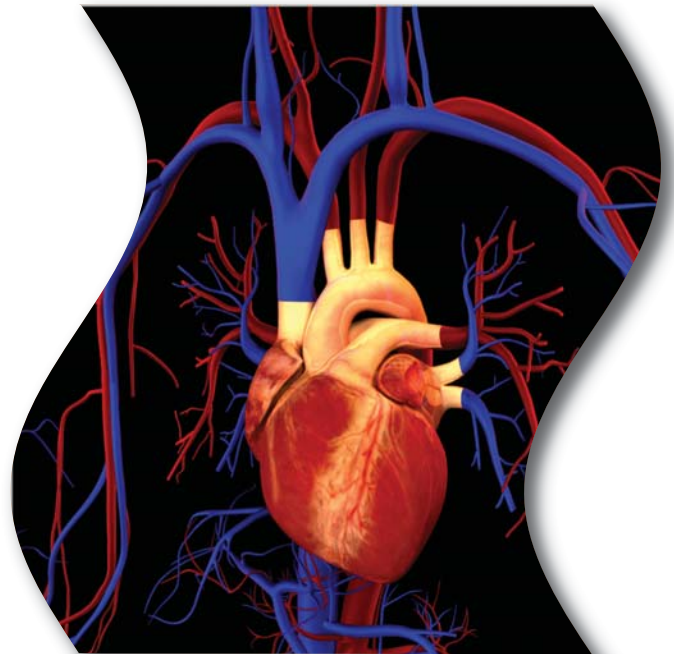
When we think about health, we tend to focus on the work that the heart and lungs do but the kidneys are as important to our bodies as these other vital organs.

The kidneys usually make around one to two litres of urine every day - the amount produced depends on how much you drink, your build, the temperature and the amount of exercise that you do.

Most people are born with two kidneys but about 1 in 1,000 is born with just one and can live quite easily with one healthy kidney. If a kidney is lost during a person's lifetime, the other can do quite well on its own and can undertake the work of both.

THE KIDNEYS HAVE MANY OTHER FUNCTIONS:

- Helping in the production of red blood cells, which are used to carry oxygen around the body
- Helping to maintain healthy bones
- Helping to regulate blood pressure in the body
- Making and regulating important hormones in the body
- Adjusting levels of minerals and other chemicals such as sodium, potassium, calcium and phosphorus



CHAPTER 2

WHAT IS CHRONIC KIDNEY DISEASE?

Chronic Kidney Disease basically means that the kidneys have, over time, lost their ability to perform as well as they used to; leading to a build-up of toxins in the blood. Severity can vary from mild or moderate to more serious cases (these can lead on to end-stage kidney disease). Doctors generally talk about 5 stages of CKD based on an individual patient's level of kidney function. The level or percentage kidney function can be estimated for any person by a formula known as the GFR.

The kidneys have a very large overcapacity - this means that they are usually capable of much more than they actually need to do and means you can lose some kidney function and still feel well. This is why some people can generously donate one of their kidneys to someone else and still live a healthy life with their one remaining kidney.

The downside to that is that if you develop CKD, you may not notice that it is happening as many patients have no symptoms. Most people can live with CKD for a long time, but if it is not managed and treated effectively, it can increase the risk of heart disease and other complications.

STAGES OF CKD		
Stage	GFR*	Description
1	90+	Normal kidney function although there may be slight kidney damage with normal or increased GFR.
2	60-89	Mild decrease in kidney function.
3	30-60	Moderate decrease in kidney function.
4	15-30	Severe decrease in kidney function.
5	Less than 15	Very severe or end-stage kidney failure that usually requires dialysis.

**GFR refers to Glomerular Filtration Rate or more simply the percentage kidney function that a person has and generally ranges from <10% (very poor) to 100% (normal) - this will be explained more on page 6.*

If you have CKD, it is important that you attend your doctor for regular blood monitoring so that the disease and its progression is monitored and that you are treated with medications that will slow or prevent your kidneys from deteriorating.

Once kidney function has been lost, it is extremely unlikely that it will recover.

SIGNS AND SYMPTOMS

Not everyone will develop noticeable signs and symptoms of CKD as it may happen over a period of years. A person can become used to symptoms such as tiredness and not realise that they are caused by a reduction in their kidney function.

With mild to moderate reduced kidney function, you may not

feel unwell. If it is more advanced, you are more likely to notice symptoms and feel ill.

Common symptoms of reduced kidney function include loss of appetite, slight nausea and increasing fatigue (one of the most common symptoms). Other symptoms can include headaches, high blood pressure, fluid retention, increase in the amount and number of times urine is passed, pain in the kidney area, reduced sex drive, lack of concentration and itching.

Not everyone with CKD will experience all of these symptoms.

Remember - you can feel perfectly healthy but blood and urine tests can show that you do, in fact, have impaired kidney function.

HOW IS KIDNEY DISEASE DETECTED?

There are two very simple tests that your doctor can do to determine if your kidney function is normal. These include a urine test and a blood test.

URINE TESTING - to check for leaking of protein through the kidneys

Testing for leaking of protein through the kidneys (called proteinuria) is a very simple way to diagnose early kidney disease

Leaking of protein (or albumin) into the urine can be the very first sign of CKD - the kidneys filtering system breaks down and proteins escape into the urine.

Too much protein in the urine is called proteinuria. The detection for this consists of a cardboard dipstick tester that is put into a sample of urine. The dipstick tester only becomes positive when the amount of proteins, mainly albumin, reaches two to four times the levels normally found in urine. Testing for albuminuria is commonly conducted in patients with diabetes.



Dipstick urine test

If protein is detected in your urine your doctor will organise further testing to see if it is due to kidney disease.

Not everyone with proteinuria will notice symptoms of it but if there are large amounts of protein in your urine, it may cause it to look foamy in the toilet. The loss of protein from your body can also mean that your body is not able to soak up enough fluid. This can result in swelling in your hands, feet, abdomen or face.

A doctor may ask you to collect your urine over a 24 hour period. You will be given a large plastic container for this purpose. The urine will be tested to calculate your kidney function. This test is not used as often these days.

BLOOD TESTING - Serum Creatinine and eGFR

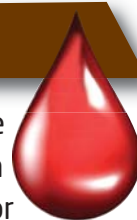
When your kidneys do not function properly, waste products build up in the blood which can be easily measured. One of these waste products is called creatinine and a simple blood test can be conducted to measure this. If the creatinine level is high, it may indicate that you have CKD.

Using the creatinine test results, your doctor can estimate your percent kidney function using a formula called the estimated glomerular filtration rate (GFR). Most blood test laboratories in Ireland can now provide the actual percentage kidney function for each patient. If your percent kidney function (or GFR) is 100 then you have normal kidney function (100% function). Whereas if your GFR is 30, then your kidney function is reduced

to 30% of normal. You should be aware of your percentage kidney function during your care. Always ask your doctor for your results of test, especially creatinine and GFR, so you are aware of your percentage kidney function.

The formula for estimating the GFR is calculated from the creatinine in the blood along with your age and gender. It is a very accurate measure for most patients. Depending on the percentage of kidney function, CKD is classified into five stages: Stage 1 to 5.

Measurements for these stages can be found on page 5 of this booklet.



WHAT CAUSES CHRONIC KIDNEY DISEASE?

There are a number of conditions that can cause damage to the kidneys and/or cause CKD. Some of the main conditions are listed below:

DIABETES

One of the known effects of diabetes is shrinking of the blood vessels. Some of your smallest blood vessels are in the kidney (see section on diabetes and CKD).

CHRONIC KIDNEY INFLAMMATION (Glomerulonephritis)

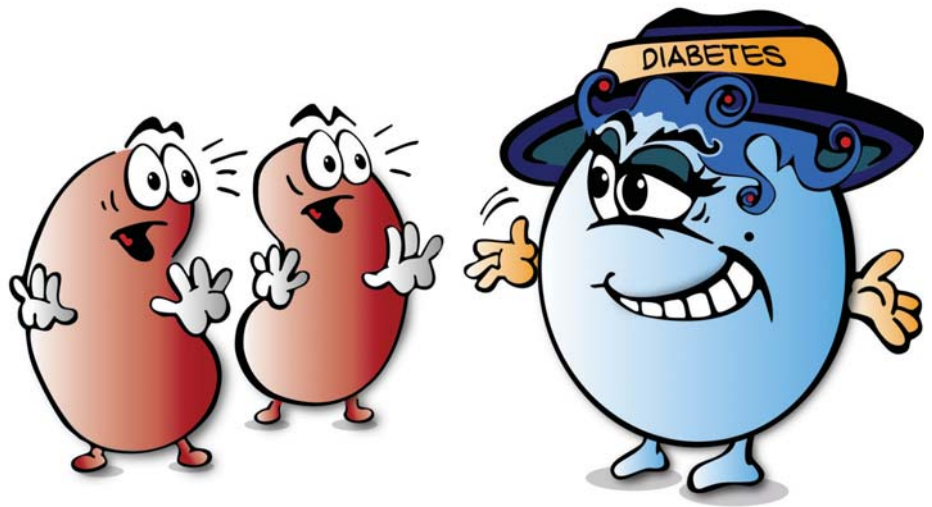
Occasionally the cause of the inflammation swelling is unknown but it has an impact on the kidneys and therefore its normal function.

HIGH BLOOD PRESSURE

Over time, this can have an impact on the blood vessels in the kidneys and reduce kidney function.

POLYCYSTIC KIDNEY DISEASE

This is a genetic condition and causes damage to the kidneys through the presence of cysts.



REFLUX NEPHROPATHY

This can happen when urine flows back into the kidney instead of through the urethra (the tube for urine to travel between the kidneys and the bladder). It is caused by a problem with the valves and if it is a severe case, it can damage the kidney's normal functions.

AGE

Apart from these conditions, kidney function is known to

deteriorate with age. Half of all healthy 65-year-olds are likely to have lost a third of their kidney function while a quarter of over 70s are likely to have lost approximately half of their kidney function.

Their reduced kidney function does not mean they will have problems with their health but allied with any other causes of CKD, it could pose a problem.

In some cases, particularly when CKD has developed to an advanced stage, it may not be possible for your doctor to give you a definitive cause for your condition.



Half of all healthy 65-year-olds are likely to have lost a third of their kidney function while a quarter of over 70s are likely to have lost approximately half of their kidney function.

Earlier in this book, we looked at how important the kidneys are in many aspects of our health. It makes sense therefore that CKD will not just impact on the kidneys themselves but will have effects on other parts of the body.

Your doctor will help monitor these aspects but you should also keep an eye out for any of the following side effects or impacts on your health.

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ANAEMIA

Blood is divided into red and white cells. Anaemia is caused by a decrease in the number of red cells in the blood. As a consequence, less oxygen is transported through the blood and this often results in fatigue.

People with more advanced CKD (usually stage 3 to 5) produce smaller amounts of a hormone called erythropoietin (EPO). This hormone is responsible for producing red blood cells.

A blood test can determine the oxygen levels in your red blood cells (haemoglobin level) to see if you are anaemic or not. If your red blood cell count is low, your doctor may recommend that you receive treatment with a hormone called EPO, which is available in an injection format. You may also be recommended to increase your iron levels through

eating iron-rich foods or taking iron supplements to assist in improving your red blood cell count.

BLOOD PRESSURE/ HEART DISEASE



When the kidneys aren't working properly, it is more likely that you will experience high blood pressure. High blood pressure can have a serious effect on your cardiovascular system - it significantly increases

the risk of heart diseases and stroke through the narrowing of blood vessels. It can also cause further damage to your kidneys. So it is very important that your blood pressure is monitored regularly and treated by your doctor.

SEX

The impact of reduced kidney function on sexuality is often overlooked as some people do not feel comfortable discussing it. However, sex is an important part of our life so there is no shame in seeking help for it or discussing it with a partner.

CKD can affect your sex drive (libido) as can other related health issues such as diabetes, high blood pressure and prescribed medications.

Some men with kidney problems may experience erectile dysfunction and some women with kidney problems may have insufficient vaginal lubrication and/or suffer from lack of libido.

HIGH POTASSIUM

Potassium levels in the body need to be kept in balance - too little or too much potassium can cause problems such as heart disorders.

Potassium levels tend to increase in people with CKD. It is important that you attend your GP or hospital regularly for blood tests to ensure potassium levels are monitored.



DIABETES AND KIDNEY DISEASE

Diabetes is a condition that is caused by having too much glucose in your blood - this can lead to other health problems and cause damage to parts of the body if left uncontrolled.

There are two main types of diabetes - Type 1, which usually develops in early life and is treated by insulin injections and diet, and Type 2, which usually presents after the age of 40 and means the body can still produce some insulin but it is either not enough or is not being properly used by the body.

Normal levels of glucose in the body are in the range of 4 and 6 millimoles per litre (mmol/L). If you have diabetes, you will experience levels outside these limits.

Risk factors for Type 2 diabetes include being overweight, being inactive and being older.

Family history is also a risk factor - if a parent or sibling has Type 2 diabetes, you then have an increased risk of developing diabetes.

One of the complications of diabetes is that it can cause kidney function to deteriorate or even fail altogether (diabetes can cause damage to small blood vessels, including those in the kidneys). The urine of people with diabetes has a high sugar content, which encourages the growth of bacteria and can therefore cause kidney infections. Around half of all people with diabetes will gradually develop some level of CKD.

Diabetes is on the increase both worldwide and in Ireland. At the moment, it's thought that 144,000 Irish people have diabetes. By 2020, it's estimated that this will increase by 62%, increasing

the number to 233,000 (ref: The Institute of Public Health's *Making Chronic Conditions Count* report, 2010).

As a consequence this means there will also be an increase in the number of people living with CKD.

Diabetes has become the most common single cause of kidney failure or end-stage kidney disease in Europe and the US so it is not a matter to be taken lightly.

If you have diabetes, you should try to stabilise the condition - by keeping your blood sugar and blood pressure levels in a safe range, by watching your cholesterol levels and eating the right type of foods, by exercising often and keeping a healthy weight. If you have been prescribed medication for your diabetes, make sure you take it.

Not only will these measures have a good effect on your diabetes but they will also have benefits for people with CKD.

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CHAPTER 3

WHO IS AT RISK?

Some people are more at risk of developing CKD than others. Being aware of the risk factors for the condition can help you to take necessary measures to try and increase the life of your kidneys and keep you feeling your best for as long as possible

DIABETES

As discussed in the previous section, diabetes may lead to CKD and people with diabetes have an increased chance of developing CKD.

HIGH BLOOD PRESSURE

If you have high blood pressure (hypertension), you have a higher chance of developing CKD. Equally, people with CKD can also develop high blood pressure so the two conditions are closely interlinked.

BEING OLDER

Kidney function naturally declines with age and people aged over 50 are also more at risk of high blood pressure and diabetes, both of which can be contributors to CKD.

FAMILY HISTORY

Not everyone with a family history of kidney disease or reduced kidney function will go on to

develop it but it can put you at higher risk. Polycystic kidney disease and Alports Syndrome are hereditary diseases that can cause kidney damage.

Conditions like high blood pressure and diabetes can also run in families. If a member of the family has kidney problems and you are worried it may affect others at some stage, it is worth talking to your doctor to have kidney function tests arranged.



BEING SEVERELY OVERWEIGHT

If you are severely overweight or obese, you have a higher risk of developing hypertension, diabetes and heart disease and, therefore, also have a higher risk of developing CKD.

OTHER RISK FACTORS

There are a number of other risk factors for CKD that are less common. These include glomerulonephritis (inflammation of the kidney's filters), nephrotic syndrome (excess amounts of protein in the urine), lupus (an autoimmune disease) and prostate obstruction (an enlarged prostate can affect normal urine drainage from the kidneys).

KNOW YOUR KIDNEY NUMBERS

If you have been diagnosed with CKD, you should have been given an indication of what degree it is at - from Stage 1 to 5 on the scale. These stages are listed on Page 5 of this book.

If you have been diagnosed in the earlier stages of CKD, you will be able to take measures to look after your kidneys and try to slow down or delay the loss of kidney function.

It is important therefore to know your numbers and this section looks at the relevant numbers for patients with CKD - Stage 1-5.

TABLE - NUMBERS FOR CKD

	Average person No CKD	Stage 3 and 4 CKD	Stage 5 CKD on Dialysis	Stage 5 CKD Transplanted
Haemoglobin	Men: 13.8 to 17.2 g/dL Women: 12.1 to 15.1 g/dL	Target 11-12	Target 11-12	Target 11-12
White cell count	4 to 11 thousand million per Litre	4 to 11	4 to 11	4 to 11
Calcium	2 - 2.5 mmol/L (serum calcium)	2.3 - 2.5	2.3 - 2.5	2.3 - 2.5
Phosphate	0.9 - 1.3 mmol/L	0.9 -1.5	1.1 -1.7	0.9- 1.5
Cholesterol	Target should be <5 mmol/l	Target <5 mmol/l		Target <5 mmol/l
Potassium	3.5 – 5.0 mmol/L	3.5 - 5.0	3.5 - 5.0	3.5 - 5.0
Bicarbonate	23 – 30 mmol/L	Target levels > 22	Target levels > 22	Target levels > 22
Parathyroid Hormone (PTH)	10 – 55 pg/ml	Levels should be treated if persistently elevated above upper limit normal	Target range are levels between 2 to 9 times upper limit normal	Is not applicable
Systolic BP/ Diastolic BP	120/80 mmHg	Target 130/80 mmHg in most patients If protein leakage, target 125/75 mmHg	Target 130/80 mmHg in most patients	Target 130/80 mmHg in most patients
Creatinine	Men: 62 to 115 micromol/litre Women: 53 to 97 micromol/litre	Elevated creatinine values	Elevated creatinine values	Elevated creatinine values
Glomerular Filtration Rate (GFR) or percentage kidney function	Approximately 100 ml/min (i.e. ~100% function)	Stage 3: 30-59 ml/min Stage 4: 15-29 ml/min	Stage 5: < 15 ml/min and receiving dialysis treatment	

CHAPTER 4

BENEFITS OF EARLY INTERVENTION

As previously mentioned, it can be difficult to diagnose CKD at an early stage as many patients may not have any symptoms until the disease is at a more advanced stage.

You may, however, be fortunate to have the existence of the disease detected early due to blood testing for something else or because you have shown early symptoms.

As with most illnesses, the earlier it is discovered, the better, as a credible plan of action can be developed between you and your doctor.

Early intervention is always the best course of action but the bottom line is that at whatever stage of CKD you are diagnosed, taking responsibility for your health and its monitoring is essential.

It is true that your kidney function may worsen over a number of years but there are steps that you can take to try and slow down that decline. You will read about these steps in the next chapter. Not only will



these actions aim to help your kidney function but they will also be good for your overall health and may help with other chronic diseases you may have like diabetes, heart disease etc.

Everybody is different so some steps will be more effective for individuals than others. Some

steps can help to slow the decline in kidney function and it is known that in some cases, they may even halt the decline for a period of time. While the exact outcome will not be known ahead of time, it is worthwhile you making efforts to stop or slow the loss of kidney function.

WHO IS IN CHARGE OF YOUR HEALTHCARE?	HOURS
Hours in a year	8760
6 visits to your doctor for half an hour at a time	3
Time you are in charge of your healthcare	8757

CASE STUDY - HOW I LIVE WITH CKD

When Peter was diagnosed with having only 25 per cent kidney function in 2007, he was initially despondent. But after he came to terms with his CKD, he decided to take whatever action he could to hold on to the kidney function he still had.

Peter, who is 60 and from Dublin, first became aware that he had kidney problems in 1993.

"My dad died the day after his 62nd birthday - he had been diagnosed with rapid cancer and he died six weeks after he was diagnosed," says Peter. "That was a big shock. He was my business partner, my friend and my dad. To watch him go so quickly - it was the end of my world in a way."

As well as grieving for his father, Peter took on the responsibility of making sure his mother was coping okay.

"I went into automatic pilot for a few months. Then in September, I collapsed. I could not do anymore. I went down to the GP who sent me for blood tests. There was blood in my urine so my GP said it could be problems with my kidneys and referred me to a specialist."

Peter went to see the consultant every six months but felt he was not given much guidance on how to preserve his kidney function.

In 2007, he brought his daughter to the GP. The doctor noticed that Peter did not look well and made an appointment for him to see another kidney specialist.

"I got an appointment within three weeks and in the meantime I got my blood tested. When I went to see the consultant, he said it is not good news - you have only 25 per cent kidney function left.

"Our first grandchild had been born a month before that so my first thought was, 'Oh my God, I'll never see her growing up'. He explained to me that at 10 per cent kidney function, I could not survive on my own and he told me that you cannot reverse kidney problems."

Peter was told that at 10 per cent kidney function, he would need dialysis or a kidney transplant.

He wanted to find out why he had reduced kidney function in case it was anything hereditary he could pass on to his three children. He was told it was probably due to an infection he had in 1993, around the time he was stressed due to his father's sudden death.

In the run up to 2007, Peter had been feeling tired.

"My only symptom was tiredness - I was extremely tired. I was heavily involved in testing computer systems at work and I put it down to burning the candle at both ends."

He was told that his blood pressure was too high (BP 160-90 mm/Hg), he was obese (Body mass index 35) and that he needed to adopt some important lifestyle changes along with medication for blood pressure. Peter's new consultant said he wanted to

see him again in a month's time and he was to bring his wife along with him.

"He probably thought I had not taken in a lot of what he had said but I was able to relate it back to her when I got home. I was devastated by the news and went into a depression for about two months.

"I was angry that my kidneys had got worse over time and that if I had

gone to this other consultant earlier, something might have been done about it. But then I started to think, hang on, I am going to fight for the little kidney function I have left. I'm going to try to improve it or hold on to it. I have got to try and do something."

Peter was told to lose two stone and he managed to do this within three months by using portion control and changing his diet. He was advised to avoid using salt on the table and adhere to a low salt diet and to walk every day for at least 30-40 minutes to boost physical activity levels.

"I joined the IKA and they sent me out booklets.



contd >

CASE STUDY - HOW I LIVE WITH CKD CONTD...

The first was about your kidneys and what you should and should not eat. I was eating everything I should not have been eating. Because my dad had died of colon cancer, I was trying to make sure it would not catch me and I was eating lots of fruit like bananas and apples and also a lot of veg. I was actually filling myself with potassium and I had not realised it."

Peter lost weight by particularly cutting back on bread and potatoes.

"You just have to change your diet so you do not eat the things that do not agree with your body. It does not bother me now if there are foods around that I cannot eat - my wife has low potassium so she eats bananas.

"They are in the house but it does not bother me at all. The only times that can be a bit harder are when everyone gets together - like Christmas and Easter - and there is chocolate and things in the house. But I just try and put them out of my mind and have zero tolerance for them.

"It took a few months to get an appointment to see a dietitian and I had changed my diet by then. She said I was doing the right things."

Peter says one of the best bits of advice he got for his health came from a nurse who was taking a blood sample.

"There was a new nurse on duty and she asked who my consultant was. I told her the doctor's name and said, 'He is looking after me'. She did not seem to hear me so I repeated his name. She said, 'No, it was the last bit you said - he is looking after me'.

"She asked me how many times a year I see the doctor and I said about four times a year and maybe for just a few minutes a time. She said, 'He might be guiding you but who is looking after you?'

"I said, 'Well, if you put it like that - it's me, isn't it?'

"The nurse said, 'Don't you forget it'. It really made me think, 'Whoa, I am in charge of my health'."

Peter was told that by 2010, he was likely to be on dialysis as he was losing 5 per cent kidney function a year. Yet now in 2013, Peter still is not on dialysis as

his kidney function is stabilised around 17 per cent.

"It was at 25 per cent in 2007 and I changed my diet. The next time I went back, it was at 20 per cent and I maintained that for four years. My belief was no, I can fight this. If I give my body the right tools, we can fight it together."

In 2009, Peter had to give up work as he was so fatigued due to his kidney problems. He and his wife were also caring for their special needs daughter.

Peter credits his diet with helping him slow down the deterioration of his kidney function.

"The diet was critical - absolutely critical. If I hadn't found the diet and stuck to it, I'd be on dialysis by now, definitely. I have a lot more energy now too."

Peter walks a lot to keep active and always opts to walk instead of taking the car if he is going somewhere local.



Peter walks a lot to keep active and always opts to walk instead of taking the car if he is going somewhere local. He does not smoke and has been a non-drinker all his life.

He now volunteers his time to set up websites for groups in the local community. He also assists the IKA in computer technology.

"I have three grandkids and I want to be around a long time to see them grow up. My ambition is to keep going the way I am going and stay away from dialysis and transplantation."

He says that being diagnosed with CKD, like any chronic illness, was hard.

"It is a shock and you naturally want to walk away from it. But when the shock wears off, you have to figure out what you are going to do. I think you have to have a positive attitude - when I was told there really was little that could be done for me, something clicked with me and I thought, 'I am going to do something for me'."

CHAPTER 5

WHAT YOU CAN DO TO LOOK AFTER YOUR KIDNEYS

This section looks at four steps to incorporate into your life to ensure you are taking an active role in your healthcare to do the very best for your kidneys.

- **Be informed and get involved**
- **Nutrition**
- **Medication**
- **Blood pressure**

BE INFORMED AND GET INVOLVED

CKD is a chronic condition - it will be with you for life. And at the end of the day, no matter how much interaction you have with the medical world to help care for your condition, it is your health, your body and your kidneys that are at stake here.

Therefore, it is vital that you play an active role in your healthcare. This means educating yourself about your condition, what causes it and how to best look after your kidneys to try and slow down the decline. This book will help you in those areas and you can also get information from other sources and speak to your doctor.

In recent years, several studies have been conducted that show that people who actively engage in their own healthcare are more likely to see positive results and live longer.

While you will get advice, help and treatment from medical professionals, it is really important that you realise that the healthcare system alone cannot slow down or stop your declining kidney function. You will need to put in time and effort too to adjust your lifestyle.

You might worry if you will be able to make changes to your lifestyle - things that you have been doing for years and might find hard to stop or reduce, like smoking or drinking. You may wonder if you can take on new challenges such as exercising more.

Remember that it takes time to change behaviour and you can only do so one step at a time, one day at a time.

We know that changing behaviour can sometimes be akin to re-wiring our brain and it can take a while to kick in.

You are nonetheless capable of change. Think back to a time in your life when you made a big change and it paid off. You can do it again.

Talk to your healthcare team about changing your lifestyle - get advice from them and do not be afraid to ask questions and check back in with them if you have any problems along the way.

Find a friend or family member who can support you through these changes (there's more on this in the Emotional Needs section later).



GETTING INVOLVED

Here are three simple ways to get involved with your own healthcare:

ASK QUESTIONS

If your doctor or consultant is giving you a lot of information and you do not understand some of it, do not be afraid to ask him/her to slow down, repeat something or explain it in simpler terms. Bring a relative or friend with you if need be. It is important that you understand what your condition is and your medical team should facilitate that - do not feel that you are being impolite by asking questions.

KEEP A PERSONAL HEALTH FILE

Your doctor or clinic will keep records of all your urine and blood tests. Sometimes you might actually bring them from one office to the other after you get tests done.

But you may find it useful to actually have a copy of these records yourself so that you can better understand the progression of your condition.

You can ask your doctor for a copy of the records - keep a file with test results and any other information about your condition, including prescriptions and appointments. Having all your information in one place will keep you organised and in touch with what is going on with your healthcare. If you ask your doctor questions, note down the answers in your health file.

If you attend a Nephrologists Outpatient clinic, you may often be seen by a junior doctor. Having your own records or file, will help you assist them through your medical history.

MEET OTHER PATIENTS

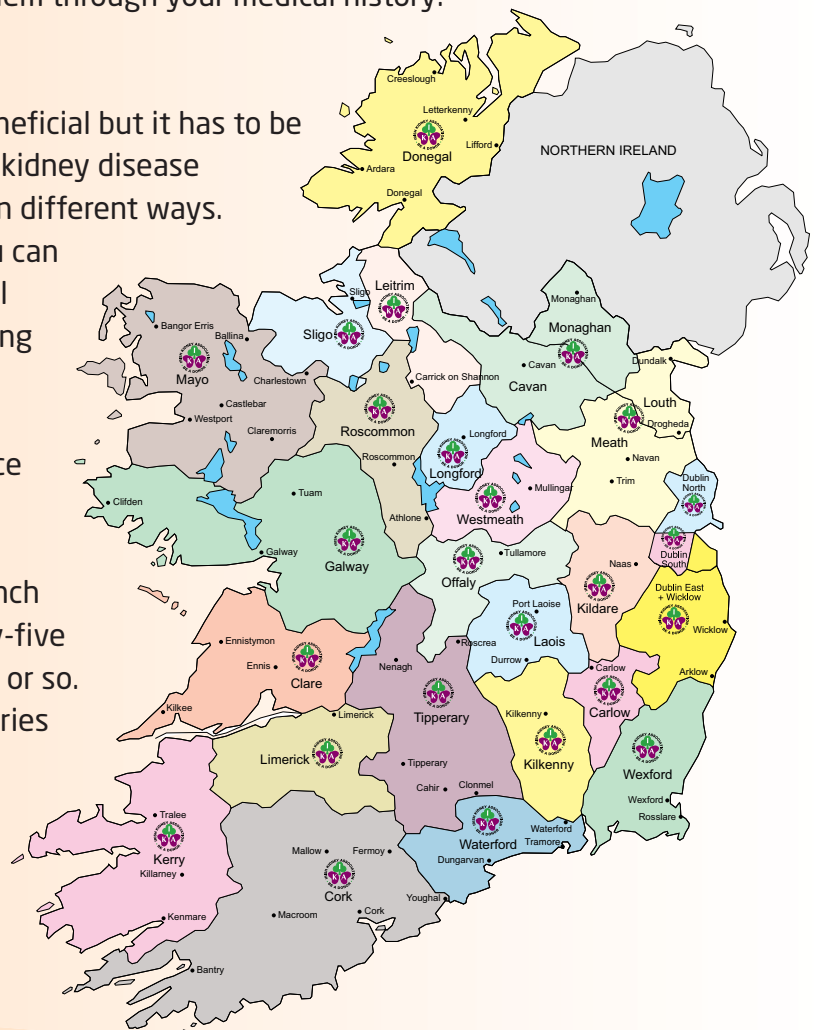
Meeting with other patients can be beneficial but it has to be done with caution. We are all unique and kidney disease manifests itself at different speeds and in different ways.

What is particularly useful is the help you can get with the interpretation of the medical jargon. Patients are very good at explaining the procedures they have also gone through. The note of caution is that you often get 'a patients' individual experience rather than the normal experience.

However a lot of people benefit from going to the Irish Kidney Association branch meetings that are held across the twenty-five branches of the Association every month or so. Full contact details of the Branch Secretaries in each area are on the IKA website,

www.ika.ie

Membership of the Association is free and you will receive a quarterly *SUPPORT* magazine which you will find very useful.



We all know that eating a healthy balanced diet is essential for optimum health. In addition to this, what you eat plays a very important role in the management of your kidney health. If you are at the early stages of reduced kidney function, nutrition can play a part in helping to slow the decline and sustain your overall health.



DIET AND KIDNEY HEALTH

When you eat food, your body uses what it needs, for energy, building and repair of the body and other body functions. It turns the rest into waste products. One of the main jobs of the kidneys is to remove these waste products from your blood. The kidneys also work at balancing a number of chemicals and minerals such as sodium (salt), potassium and phosphate in the blood. When kidney function is reduced, dietary advice aims at minimising the build-up of waste products in the blood and helping to keep all chemicals and minerals in balance.

GETTING HELP

If you have CKD you should see a qualified dietitian to get advice on the diet most suited to your individual needs.

The following information will give you an overview of the renal diet (diet for reduced kidney function). It briefly explains what is advised in relation to some of the most important components of the diet; protein, carbohydrates, fats, salt, potassium, phosphate and fluid. Bear in mind that dietary advice can sometimes differ for people who have other conditions in addition to CKD (e.g. patients with diabetes will need some additional modification to the diet).

Dietary advice may also differ for people with CKD at different stages. For example, patients in

If you have CKD and one or more other chronic conditions, you should see a qualified dietitian to check that the dietary advice you are following isn't coming into conflict with your other conditions.

the late stages of reduced kidney function may have need for greater restriction of minerals such as potassium and phosphate than those in the early stages.

All patients have different dietary needs so it would be necessary for your doctor to refer you to a dietitian to discuss your individual needs.





PROTEIN

Protein is an important building block for the body (for muscles, bones, tissue and skin) so you need to take in the right amount on a daily basis. How much protein you need depends on your body size and is individual to each person.

The main sources of protein in your diet should be meat, chicken, turkey, fish, eggs or dairy. Eating large amounts of protein will affect the build-up of waste products in your blood and hence it is important to have a moderate protein intake. Too little protein can also be harmful as it may cause reduced muscle strength. Your dietitian will advise you on the amount of protein that you need to maintain health.

FATS

There are lots of different types of fats and some fats have real health benefits, such as helping our bodies to absorb vitamins A, D, E and K, others play a role in protecting the heart. Fats are a source of energy and are essential building blocks for the cells in your body. For general health a low fat diet is advised but it is not just about the total amount of fat that you eat but the kinds of fat that you have in your diet. Fats can increase your cholesterol levels - there are a number of different cholesterol in the body but the two main types are HDL, referred to as good cholesterol, and LDL, the bad type of cholesterol.

Saturated fats can raise bad (LDL) cholesterol levels, which can have an adverse effect on heart health.

Saturated fats are often solid at room temperature and are mostly found in dairy products such as hard cheeses or butter and meat products like sausages, burgers and fat on meat.



CARBOHYDRATES

Carbohydrates are the main source of the body's energy. The amount of energy you need depends very much on your individual circumstances - your age, gender, weight and level of physical activity.

Rich sources of carbohydrates include breads, rice, pasta, noodles, cereals and potatoes. Most carbohydrate foods do not cause problems for the kidneys and do not require to be restricted in the renal diet. The exception to this is potatoes. In the later stages of CKD potatoes may have to be limited because they are high in potassium. Because a number of other foods are limited in the renal diet it is important to ensure that a wide variety of carbohydrate foods are used and should be included in each meal.

For general health it is better to limit the amount of sugary carbohydrates such as pastries, soft drinks, and sweets.



Trans-fats are also considered to be bad for your health and can raise cholesterol levels. They are found in many processed foods that contain shortening or partially hydrogenated fats e.g. biscuits, pastries and some fast foods that have been fried or battered, like chips or burgers.



Good fats include polyunsaturates and monounsaturates. The former are found in oily fish (e.g. mackerel, salmon and trout), and certain plant oils, including sunflower oil.

Monounsaturated fats are found in olive oil and rapeseed oil. Having a balance of good types of fat in your diet is important for the health of the blood vessels in your kidneys as well as in your heart.



SALT

Most people, whether they have kidney problems or not, eat too much salt every day. If you do have CKD, you will need to watch how much salt you take in, as too much salt can increase your blood pressure.

To reduce salt intake, do not add salt (including salt substitutes) to your cooking or to food on the table. Avoid processed foods that contain a lot of salt, i.e. ham, bacon, sausages, soups, stock cubes, crisps and packet sauces and try to use other herbs and spices instead of the salt shaker.

POTASSIUM

Potassium is a mineral and electrolyte in the body that is important for nerve, heart and muscle function.

High potassium levels in the body can pose a problem for kidney health and for other parts of your body including your heart. If this is the case, your doctor or dietitian will advise that you reduce your intake of foods that are rich in potassium including bananas, dried fruit, potato and potato products, i.e. chips, crisps, fruit juices, chocolate, coffee, nuts, peas, beans, avocado and spinach.

PHOSPHATE

Phosphate is a mineral that makes up 1% of a person's total body weight. It is present in every cell of the body, but most of the phosphate in the body is found in the bones and teeth.

High phosphate levels can occur in CKD and increase as the kidney function declines further. High phosphate levels are linked with cardiovascular disease and a higher risk of death.

If your levels of phosphate are high, your dietitian will advise you how to reduce the amount of phosphate in your diet. Foods that are high in phosphate are processed meats and poultry, cola, milk, cheese, yoghurt, nuts and soda bread.

FLUIDS

If you are in the early stages of CKD, you will be advised to stay hydrated as normal. Water is a vital part of life and we need it for our bodies to work properly - it helps us to get rid of waste products from the body and for moving nutrients around the body.



If your kidney function has declined significantly, your doctor may instruct that you restrict your intake of liquids. If this is the case, you will need to make sure that you do not eat foods that encourage a thirst (particularly the case with salt).

Remember that you can stay hydrated through the intake of different kinds of fluid - not just water. No added sugar squash, milk and tea also count.

You should drink to satisfy your thirst and if you start to feel dehydrated (common signs are being thirsty, tired, dizzy and having lack of concentration). If you have an illness such as fever, vomiting or diarrhoea, you may want to increase your hydration levels as dehydration can worsen your kidney condition.



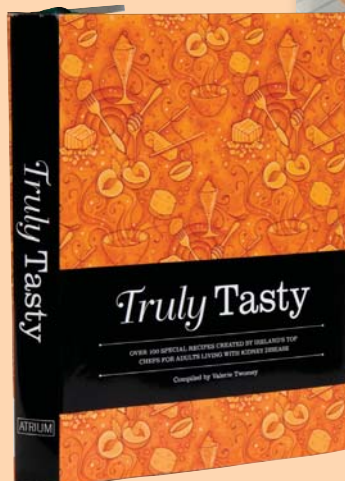
TOP TIP

PLAN YOUR MEALS

Planning meals in advance is a good way to ensure that you and your family eat healthy meals throughout the week. Choose what meals you are going to make before writing up a shopping list.

When you have the right foods to hand in the fridge and larder, it is easier to prepare suitable meals. There is less temptation to eat convenience foods or skip meals.

One resource for recipes is the book 'Truly Tasty'.



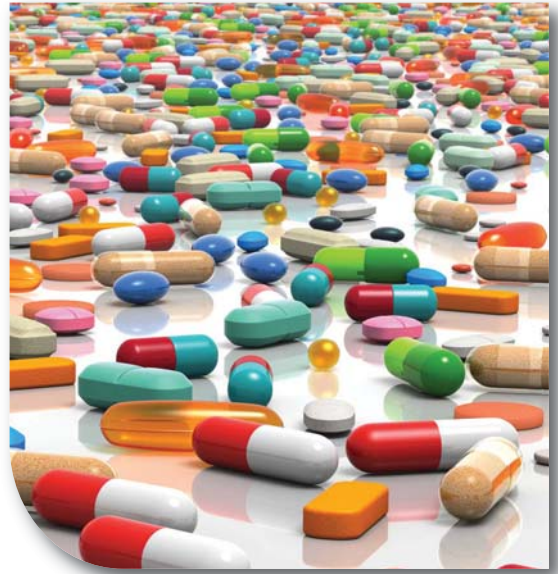
It contains more than 100 special recipes for people living with kidney disease - all created by Ireland's top chefs (www.trulytasty.ie)

www.irishkidneydiet.ie is also a great resource for advice and recipe ideas for renal patients.

MEDICATION

At some stage of your CKD, you will be prescribed medication. You may be prescribed more than one medication. It's important that you understand what the medication is treating and how you should take it. Ask your doctor or pharmacist if you are in any doubt.

Medications have two names - one is a brand name (which is what most people use to refer to it) and the other is the approved pharmaceutical name (which can sometimes be trickier to say, spell and remember). For example, ibuprofen is the name of a type of painkiller but one brand of it is Nurofen.



HERE ARE SOME OF THE MOST COMMON MEDICATIONS USED FOR CKD:

ASPIRIN

You may be prescribed a low dose of aspirin to improve blood circulation. Don't take this without your doctor's advice as aspirin can affect the clotting abilities of the blood and may cause bleeding.

BLOOD PRESSURE TABLETS

These will help you keep your blood pressure levels under control. There are many different types of blood pressure medications available including diuretics, ACE inhibitors, beta blockers and more. Your doctor may prescribe one or more of these medications depending on the level of your blood pressure (hypertension) and/or any related conditions you may have. You should listen closely to the advice they give you.

DIURETICS

These increase the flow of urine in the body and are sometimes used to help the kidneys remove excess water from the body. Blood pressure medications sometimes have an inbuilt diuretic contained within them - talk to your doctor or pharmacist if you need further information on this.

ERYTHROPOIETIN

You may need to take an injection of the hormone erythropoietin (EPO) if your kidneys do

not produce enough of it. EPO helps stimulate red blood cells. If you are suffering from anaemia, you may need to take it.

FOLIC ACID

This is used to produce red blood cells and can be combined in a supplement with vitamins B12 and B6.

IRON

If you are anaemic, you may need to take iron supplements to boost your levels. If you cannot tolerate iron tablets or you are still low in iron after taking them, your doctor may prescribe intravenous iron.

PHOSPHATE BINDERS

Your doctor may prescribe a phosphate binder for you - to be taken with meals and snacks. This medication helps control the levels of phosphate in your body. It soaks up phosphate and traps it in the gut where it can then leave the body as a waste product.

VITAMINS

Due to your reduced kidney function, you may be deficient in some vitamins so your doctor may recommend that you take supplements.

MEDICATIONS TO WATCH OUT FOR OR AVOID

Your doctor or your pharmacist is the best source of advice on this but, in general, you should avoid the following medications if you have CKD:

- NSAIDS (anti-inflammatory medications like ibuprofen);
- Alka seltzer or baking soda (high in sodium);
- Milk of magnesium or antacids containing magnesium, laxatives and supplements that have potassium or magnesium.

Always check the ingredients on herbal medicines as they can be contraindicated and many interact with prescribed medications. Please talk to



your doctor if you are considering taking any herbal remedy.

Right:
To help you keep track of your medication download a Smart phone app medication reminder



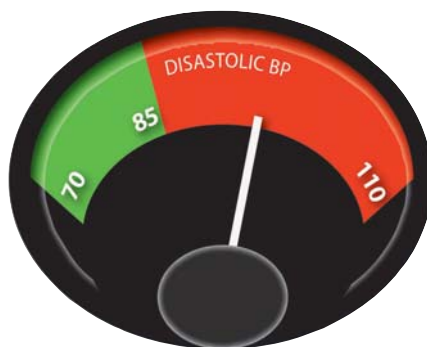
Left and below:
Handy 7 day pill organisers



TOP TIPS FOR TAKING MEDICATIONS

- If you are seeing a healthcare professional for the first time, make sure to tell them what medications you are currently taking.
- Always follow the instructions on your medications - in terms of the dosage and how often you should take them. Also, read the instruction label if one is provided.
- Do not use medications that are out-of-date and never take a medication than has been prescribed for someone else.
- Do not stop taking medication without checking with your medical team. If you feel you are suffering a side effect, do let them know.
- Having a list of your current medications on your person, in your wallet or handbag is always recommended. Smart phone apps are also a useful place to store the information.

WATCH YOUR BLOOD PRESSURE



WHAT IS BLOOD PRESSURE?

Your heart pumps blood away from the heart to the rest of the body, in vessels called arteries and it returns to the heart in vessels called veins. Blood pressure is a measure of the force blood exerts on the arteries as it is pumped around the body.

When the heart contracts, during each heartbeat, it is called systolic blood pressure. When the heart relaxes, between beats, it is called diastolic blood pressure. When you have your blood pressure taken, there will be a reading for the systolic pressure (the higher number) and for the diastolic pressure (the lower number).

Blood pressure can go up and down during the day. A normal blood pressure reading for a healthy adult is around 120 systolic/80 diastolic.

HIGH BLOOD PRESSURE

The main cause of high blood pressure is narrowing of the arteries and this can occur as we get older or because of our eating and lifestyle habits. However, high blood pressure can also run in families.

Having high blood pressure often shows no symptoms, so you could have it for a long time

DID YOU KNOW?

High blood pressure is on the rise in Ireland - the Institute of Public Health (IPH) predicts that there are now 1 million cases of high blood pressure in Ireland and this will grow to almost 1.3 million cases by 2020. It is not too late to buck the trend though!

and be completely unaware of it. The best way to tell is by having regular checks with your GP, practice nurse or pharmacist.

If you want to keep track of your blood pressure more regularly, it is possible to buy a blood pressure cuff, use it at home and record the results you get. It is still vital though to get checks done with your doctor when you visit him or her.

HIGH BLOOD PRESSURE AND KIDNEY HEALTH

High blood pressure can cause damage to the blood vessels and filters in the kidneys and can put undue pressure onto the cardiovascular system. People who have kidney conditions have an increased tendency to have high blood pressure and must take steps to try and reduce it.

HOW TO GET YOUR BLOOD PRESSURE UNDER CONTROL

Your doctor may prescribe you with a blood pressure medication straight away or, if identified at an early stage, he or she may advise you to try to change your lifestyle first before using medication.

Even if you are prescribed blood pressure medication, called anti-hypertensives, you should also try lifestyle changes to reduce your blood pressure levels. Here are a few ways to bring your levels down - you can take a closer look at some of them in the next chapter.

- Lose weight
- Increase physical activity
- Stop smoking
- Cut down your alcohol intake
- Manage your stress levels
- Eat a healthy diet
- Reduce your salt intake

REMEMBER

Keeping your blood pressure down is one of the most important - if not the most important - aims for people who have kidney disease.

CHAPTER 6

WHAT YOU CAN DO TO LOOK AFTER YOUR GENERAL HEALTH



EXERCISING

BENEFITS

One of the side effects of CKD is that you may feel fatigued or lack energy due to anaemia. This means you will feel lethargic and less inclined to stay physically active.

But it is vital that exercise is part of your daily life - not only for your physical well-being but for your mental well-being.

Being physically fit strengthens your heart and lungs and improves your circulation. It can also help control your weight, help your digestion, lower your blood pressure and cholesterol levels, and reduce your stress levels.

For a kidney patient, exercise has a positive effect on all of the areas above along with building your bone health, helping you to sleep better and

lowering your chance of developing diabetes (and it will improve control of your blood sugar levels if you are a diabetic).

In addition, there is a growing body of evidence that shows that exercise may help to prevent the negative side effects of kidney disease, like muscle loss and tiredness.

Physical activity helps you to produce more feel-good hormones - you will release endorphins as you exercise and you will also reduce any excess amounts of the stress hormones adrenaline. There is increasing evidence that exercise can also help people who are dealing with depression or anxiety and this may be a factor for you.

Being outdoors while you exercise also boosts levels of Vitamin D, which will make you feel better.

DID YOU KNOW?

We often complain that we do not have time to exercise but the average Irish person watches television for 18.7 hours each week. If you substitute even a quarter of that time to exercise, you will be well on the road to physical fitness.



GETTING GOING

If you are in good general health, there is no reason why you cannot exercise but always check with your doctor if you are in any doubt as to how much you should push yourself during physical activity.

Build up gradually if you have not exercised recently and remember, the saying 'No pain no gain' should not be taken as advice! If exercise begins to hurt, stop what you are doing straight away. Always warm up before exercising and take your time to slowly wind down when you are finishing your activity.

HOW MUCH EXERCISE SHOULD YOU BE DOING?

This very much depends on your age, health status and existing physical fitness. However most people should aim for 30 minutes of exercise every day of the week.

This does not have to be taken as a 30 minute block although there are more health benefits if you do so - if the only option for you to exercise is to split it into two 15 minute blocks, then that is better than doing no exercise at all. If you need to lose weight, then you will probably need to do more exercise over the course of a week.

Build up gradually if you have not exercised recently and remember, the saying 'No pain no gain' should not be taken as advice!

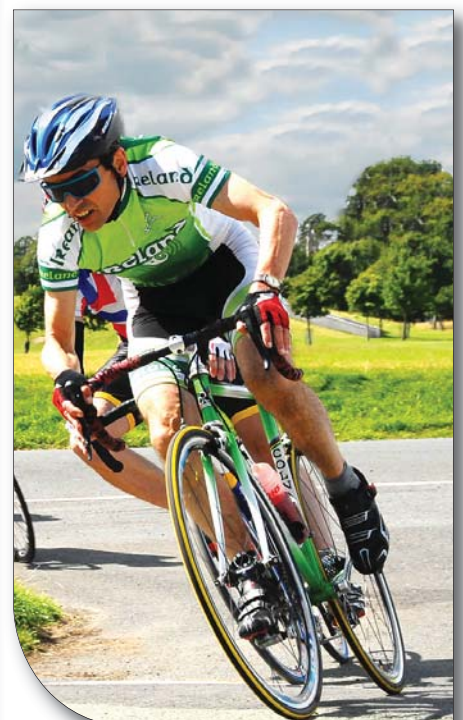
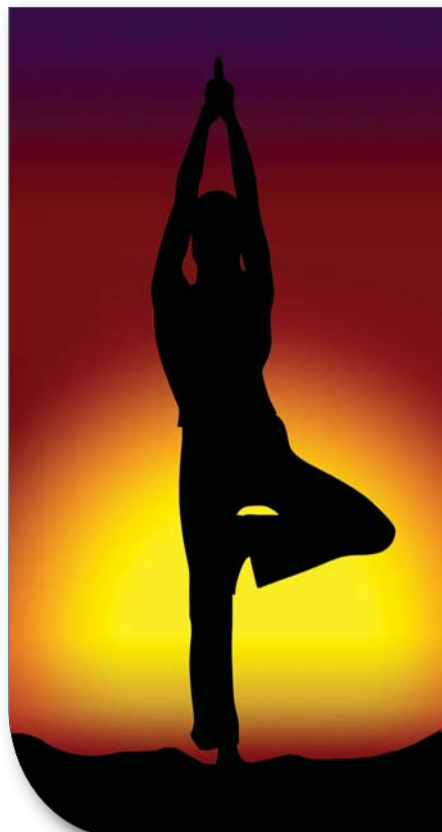


WHAT TYPE OF EXERCISE SHOULD YOU DO?

There are two main types of exercise - cardiovascular and resistance. Added to this are flexibility and balance type exercises including Yoga and Pilates.

Cardiovascular activity, as the name implies, helps your heart and lungs to work more efficiently and will also improve blood pressure and help you burn fat for weight loss.

Good cardiovascular exercises include walking, running, cycling, swimming, aerobics and team sports.





Resistance exercise really focuses on the muscles and encourages them to become stronger. It also improves blood pressure, insulin sensitivity and diabetes control.

Resistance training typically uses weights or machines with resistance (such as a spin cycling class) but you can do weight training yourself at home with smaller weights or even bottles of water or tins of beans. Exercises like squats or push-ups also involve resistance training.

EXERCISE TIPS

- Exercise until you are pleasantly tired but do not push to exhaustion. The right level will leave you breathless but not speechless. So if you are walking briskly with a friend, you should be able to keep up a conversation!
- To keep yourself motivated to exercise, keep a diary where you can note down your fitness plans for the week and check them off when you have achieved them.
- Choose the right time of day for you to exercise - some people prefer to get moving in the morning while others prefer to leave it till the afternoon or evening. It is generally recommended that you do not exercise within two to three hours of going to sleep as the activity may affect your ability to nod off.



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- Remember that every day activities also count. Use the stairs instead of taking the lift and get off the bus a few stops early to give yourself a bit of a walk. Other everyday tasks that will help you stay active include gardening, playing with the children or grandchildren, painting, washing your car, dancing and vacuuming!
- Anyone can get involved in the training events organised by the Irish Kidney Association in connection with the Transplant Games. And there is also the **Run for a Life** event every autumn, which raises funds for the IKA.



It can take time to come to terms with a diagnosis of CKD. Having the right emotional support can help tremendously. We spoke to Mike Kelly (right), who is a psychotherapist and Coordinator of Counselling Services for the IKA.



Q. Being diagnosed with CKD can bring up a lot of emotions for the person?

That is correct. We respond, not just physically but also psychologically and emotionally to a diagnosis of reduced kidney function. In life, we carry certain assumptions, one of which is that we expect always to be healthy. With a diagnosis of CKD, this assumption is shattered.

When we think of illness, we usually think of it in acute terms such as going to the hospital, being treated and discharged

home. When diagnosed with a chronic condition, this mindset is challenged. With a chronic condition, we have to face the unpleasant reality that while there may be treatment, there is no cure. It is a life changing and lifelong diagnosis.

Initially our reaction to a diagnosis is one of shock. The world as we have known it and felt comfortable with is changed forever.

Added to this, the way we think about ourselves will also change. Anxiety levels may

increase as we begin to immerse ourselves in a world that is unfamiliar and uncertain.

Our psychological equilibrium, that balance that allows us to function on a daily basis, is threatened. This is to be expected and will happen when we experience any trauma in life. However, with help, support and the willingness to adapt, in time this psychological equilibrium will be restored.

Q. Does denial sometimes set in after a diagnosis?

Denial is a common reaction and quite normal. By denying what is happening, we create a space that allows us to think. While denial is appropriate in the early stages, it becomes a problem if it is prolonged.

As one patient said, "Being in denial means not having to react to change. I can ignore the diagnosis and believe it is not real". While this may be an appropriate reaction at an initial stage, it is easy to see the difficulties it creates if it becomes a permanent attitude.





Each of us is unique, and how we react to diagnosis will vary. However, there are some common reactions which include sadness, anger, depression and feeling isolated.

Q. What if your reaction is that you feel overly emotional?

Often after diagnosis, people can feel emotionally sensitive and fragile. This is quite normal. Our minds can be assaulted by questions that at this point have no answers. How long will I have this condition? How is it going to affect my life? Will I be able to continue working? Will I be able to go on holiday? How is it going to affect my family? Am I going to die?

It feels like we embark on an emotional rollercoaster but in time, for most, when these and other questions are answered, our emotions will settle.

It is important to recognise that one of the common physical symptoms of CKD is fatigue.

It is important to recognise that one of the common physical symptoms of CKD is fatigue. In any situation when we feel fatigued, it affects how we feel emotionally as well.



Q. Do you have advice for someone who has been diagnosed, is coming to terms with it and is trying to move on in practical ways with their condition?

A quote from a patient may help...*"I reach a stage where I acknowledge and accept this treatment is necessary and while it places limits on my life, it doesn't stop me from living."*

People need time to accommodate to this new situation in their lives, whether it be starting treatment or having a transplant. Often what people want is someone to listen to them, who can communicate openly with them, who can answer their questions, and who can support them through the difficult emotional and physical moments.

Education is very important, particularly educating yourself about your condition. This is empowering and for most, will lead to a return of confidence and feeling better about and within themselves.

Q. What about people's expectations - do they need to manage these?

People can have high expectations of how their life will be and don't take into sufficient account how CKD may impact on that. For example, if, due to your condition, you are unable to work anymore, it will have a knock-on effect on the family.

It may also raise a question about identity; who am I if I cannot work? A significant drop in income may put pressure on the family unit which may make it difficult for the family to make ends meet. If the male partner has to leave his job due to illness, the female partner may have to bear the full financial burden or find a job out of necessity. This role reversal can change the dynamic of the relationship between the two.

People may also need to understand that some of their expectations are not going to be met and they will need to adjust to this. At the same time, they may be surprised by just how much they can do.



Q. Can it be difficult to tell other people about a diagnosis? Do you have any advice?

It is difficult to give general advice and it is really up to the individual in terms of who they want to tell about their diagnosis - their friends, family, work colleagues, acquaintances and so on.

Telling others can certainly make the diagnosis seem more real. People will worry about how others will react, what they will say or whether it's going to change relationships or work situations.

Telling others may help in some ways as CKD is not a visible condition. If you walk down any street in Ireland, you can't pick out the kidney patient. Some people may not understand that you're sick as you look good.

Q. Some people may withdraw into themselves after a diagnosis. Is it important to talk about it to someone?

When we experience trauma, we may want to retreat and find a place inside of us where we feel safe. This can make us isolated from others and can be a big change, especially for someone who's always been very outgoing and now is withdrawn and quiet.

Talking to someone else can help to break down the fears and anxieties that the person is going through on their own.

Support is available in a lot of different ways - a good friend or relative who will lend a listening ear, someone who has a similar condition and has gone through

the same things you are experiencing or a professional counsellor who is non-judgemental and will give you the space to talk about what's going on with you.

This needs to be done at the individual's own pace and should not be forced.

Family members can be great carers and that can be very helpful. Yet caring is demanding and sometimes families can end up doing too much for the person who has the kidney condition, which can erode their self-confidence and belief that they can do things for themselves.



Q. What about the family and friends of the person who has been diagnosed - do they need emotional support too?

It's important that family members and close friends get emotional support as well. It can affect them tremendously but they don't want to show it because they're supporting the person who has the condition.

A diagnosis raises all sorts of issues with a family. It is important that they be talked about openly and honestly. Family members should seek support from a friend, someone they trust or a professional counsellor.

The IKA has branches in each county that can help with peer support and advice.



NOT SMOKING



It is well known that smoking tobacco constricts the small blood vessels in the body, thereby raising your blood pressure. It is also harmful for your cardiovascular health. People with CKD should avoid smoking for these reasons but also because it can affect the small vessels in the kidney filters, thereby reducing the kidneys' abilities to work effectively.

It is also known that if your kidney function deteriorates to the extent that you need dialysis, smoking can increase the risk of complications.

Giving up cigarettes is not an easy task for most people but there are supports on hand and it is definitely never too late to quit.

TIPS TO HELP YOU QUIT

- Choose a day to give up smoking and get advice beforehand.
- Have a clear out - on the evening before your quit day, get rid of all cigarettes, lighters, matches and ashtrays.
- Put the money you would normally have spent on cigarettes into a jar - treat yourself with the money you save.
- Take more exercise - being more active when you are trying to give up smoking increases your chance of success.
- Get help - phone the **National Quitline** on **Freephone 1800 201 203**. They can give you help and advice on how to quit smoking

ALCOHOL CONSUMPTION

Whether you can drink alcohol and what amount you can drink will depend very much on your individual case. Some studies suggest that alcohol causes no direct harm to the kidneys but it can be dangerous if you already have kidney problems and it does have an effect on things such as blood pressure and heart disease.

One side effect of alcohol is that it can make your kidneys produce more urine than normal (some drinks such as beer are particularly well-known for this). Having to go to the toilet several times in one night may put your kidneys under undue pressure and disturb sleep patterns.

If you have advanced CKD, you may not tolerate alcohol very well and it may make you feel unwell.

The main advice about alcoholic consumption is to take it in moderation and be aware of how your body responds to alcohol. Always check that you can take alcohol alongside any medications you are on.



KEEPING A HEALTHY WEIGHT

When it comes to kidney disease, it is really important that you maintain a healthy weight. Being either overweight or underweight can pose problems for your health that will have a knock-on effect on your kidneys.

Being overweight or obese increases your blood pressure, increases your level of bad cholesterol, makes your heart and lungs work harder and also increases your risk of developing diabetes.

On the other hand, if you are underweight, you run the risk of malnutrition. Not having the right nutrients in your body can affect your immune system and make it harder to fight off infection. It will also leave you feeling listless and reduce your muscle mass and strength.

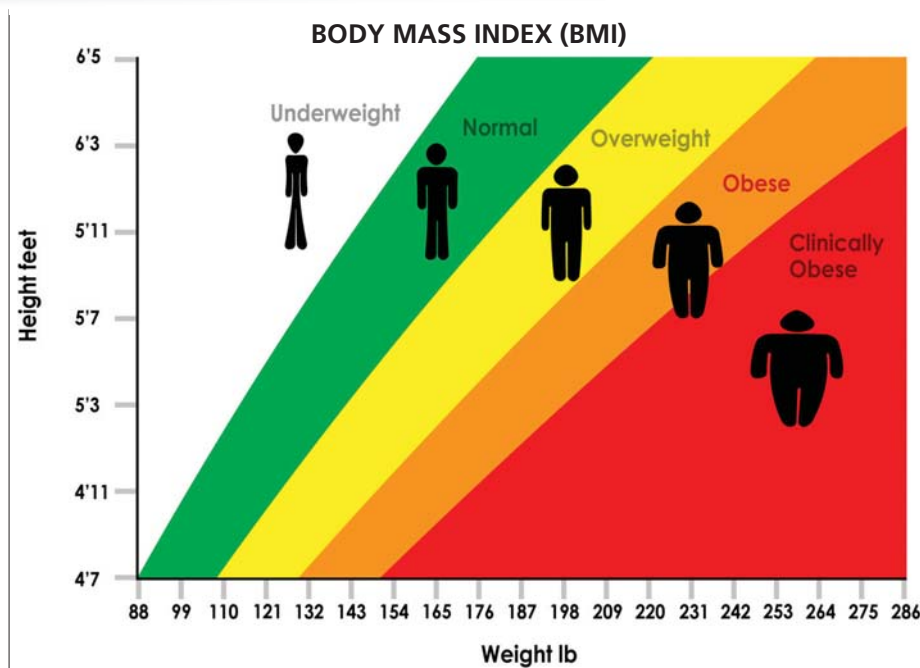
SO WHAT IS A HEALTHY WEIGHT?

There is no perfect healthy weight - it very much depends on your gender, age, height, build and your activity levels. One guideline for healthy and unhealthy weights is the Body Mass Index (BMI).

If you have a BMI of 30 or over, you are classified as obese. A BMI of 25 to 30 is classified as overweight, an ideal BMI is 18.5 to 24.9 and an underweight BMI is anything below 18.5.

If your BMI is either underweight or obese, you should take steps to get back to a healthy weight.

You can work out your BMI at www.bmicalculator.ie or by using this formula above:



BMI FORMULAS

METRIC BMI FORMULA

Weight in kilograms / (height in metres x height in metres).

For example: if you are 1.75 metres high and weigh 73 kgs then the formula will read:

$$\text{BMI} = 1.75\text{m} \times 1.75\text{m} = 3.062$$

$$73\text{kgs} \div 3.062 = 23.8$$

Your BMI would therefore be **23.8**.

IMPERIAL BMI FORMULA

Weight in pounds / (height in inches x height in inches) multiplied by 703.

For example: if you are 69" high and weigh 161 lbs then the formula will read:

$$\text{BMI} = 69" \times 69" = 4761$$

$$161\text{lbs} \div 4761 \times 703 = 23.8$$

Your BMI would therefore be **23.8**.

YOUR WAISTLINE COUNTS TOO

As well as working out your BMI, you should measure your waistline as fat around your tummy region is considered a big risk factor to your health. Having a waist size greater than 32 inches for a woman or 37 inches for a man is thought to be a clear indication that the person is carrying excess weight.



HOW TO LOSE WEIGHT

For any person who wants to lose weight, the key thing to remember is that you will need to use more energy than you consume. Therefore a combination of healthy eating and regular exercise is the best way to lose weight in a way that is sustainable over the long-term.

Crash diets and fad diets are only effective in the short term and usually any weight that you lose soon re-appears.

CHAPTER 7

WHEN AND IF MY KIDNEYS FAIL

If you progress to a situation where you have CKD Stage 4-5 and/or have lost most of your kidney function (<15%), you may experience symptoms that you have not had before.

These can include increased fatigue, nausea, itching, swelling, lower back pain, problems passing urine and increased blood pressure.

If your kidneys start to fail, you will be referred to a nephrologist (kidney specialist) to talk about the options going forward. These include dialysis and kidney transplantation.

DIALYSIS

The kidneys wash the blood and separate out waste products to be eliminated from the body. When the kidneys can no longer complete this necessary service, something else has to take its place - dialysis.

HAEMODIALYSIS (filtering of blood via the blood stream) involves using a special machine - blood is drawn from your arm via a tube into the dialysis machine. The machine filters the waste out of your blood and then returns the blood back to your body.

This process takes around four hours every time and most people need to attend a hospital or clinic at least three times a week. However, more recently you may be able to avail of home dialysis depending on your condition and willingness to choose a treatment you can manage yourself.



The **Irish Kidney Association** and **Beaumont Hospital** produce six other Patient Support Books. You can access the books at **www.ika.ie** or call **01-6205306** for copies.



PERITONEAL DIALYSIS works in a different way - a special fluid is fed into the abdominal cavity (a part of the body called the peritoneum) through a catheter and tube. This fluid cleanses the blood by absorbing the waste through the abdomen's mucous membrane.

This type of dialysis is continuous (continuous ambulatory peritoneal dialysis or CAPD) and changing the fluid can be carried out by the patient themselves during the day time or can be carried out by a small machine at night while he or she sleeps (automated peritoneal dialysis).

Dialysis has an impact in terms of the amount of time the treatment consumes every week and some people report feeling tired after having dialysis. However, it is a crucial treatment and there are supports in place for patients who need advice or support while going through dialysis.



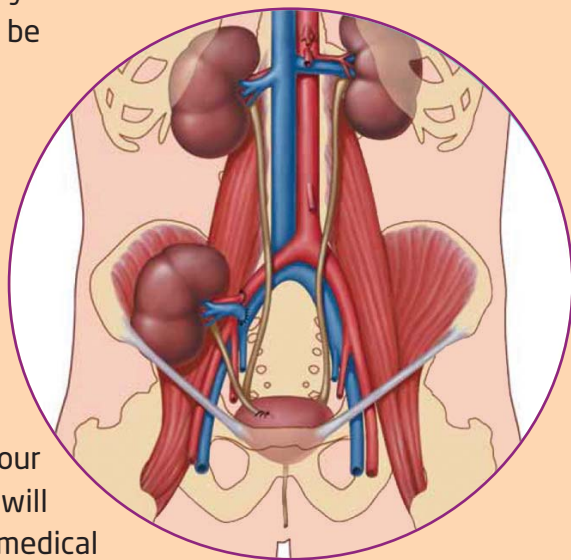
KIDNEY TRANSPLANTATION

For someone who has developed kidney failure (or end stage kidney disease, or Stage 5 CKD), either type of dialysis will keep their body functioning and therefore keep them alive. A kidney transplant, when deemed viable, is the best long-term treatment for patients whose kidneys are no longer functioning.

The idea of having a kidney transplant may seem daunting but the procedure has been carried out for many years and is carried out frequently.

Not everyone will be suitable for kidney transplant - you will have to undergo an assessment to see if you are.

To receive a kidney transplant, you must be in reasonable good health, apart from your kidney disease. You will have to go through medical tests to determine your health.



The next stage is that you will be placed on a kidney transplant waiting list - you will be put in touch with a transplant co-ordinator who will detail the process with you.

There are two different types of kidney transplant. A deceased donor kidney transplant, and a living donor kidney transplant. The IKA/Beaumont book *Kidney Transplantation - A Guide for Patients* is one of the sets of books in this series. *Thinking about Donating a Kidney* is another book in the series that your relatives, or a close friend, might consider reading. If you are called for a kidney transplant, this would take place at Beaumont Hospital in Dublin. The IKA have a Patient Support Centre on the hospital campus that all renal patients and their families can avail of.

You will be closely monitored after your operation for risk of infection and to check if the kidney is accepted or rejected by the body. You will be given medications to help give the kidney the best chance of being accepted by the body by reducing the immune system.

A patient may consider not going forward for dialysis and/or transplant. In such circumstances, the patients will be made aware of the possible consequences of such a decision and the support services that are available. If this is the case, conservative treatment will be used (diet and medication to try and manage kidney failure).

CHAPTER 8

GLOSSARY

Albumin	Type of protein. Albumin is a measure of the amount of protein reserves in the body which helps to maintain blood volume and blood pressure. A test for albumin in the blood is often used to determine if someone has malnutrition or inflammation related to kidney disease.
Amino Acids	Substances that make up protein and are vital for good health.
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.
Artery	Vessel that carries blood from the heart to the rest of the body.
Blood Pressure (B/P)	Pressure that the blood exerts against the walls of the arteries as it flows through them.
Cardiovascular Disease	Diseases and conditions of the heart and blood vessels - includes heart disease and stroke.
Chronic Kidney Disease	Progressive condition in which the kidneys are not functioning effectively. Chronic kidney disease is irreversible but can be slowed.
Complete Blood Count (CBC)	Test that includes red blood cell count, white blood cell count, haemoglobin level and platelet count, among others.
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.
Dehydration	Not enough water in the body, which can cause symptoms including faintness, lack of concentration and fatigue.
Diabetes	Metabolic disease that is caused by an absence or lack of insulin in the body. Creating excesses of glucose in the blood.
Dialysis	Artificial process which removes waste products and water from the blood by passing it through a filtration machine.
Diuretic	Medication that increases urine output from the body. Also known as 'water tablets' or 'fluid tablets'.
Erectile Dysfunction (ED)	Difficulty getting or maintaining an erection during sex. Some men with kidney problems may experience ED.
Erythropoietin (EPO)	Hormone involved in the production of red blood cells. A lack of this hormone can cause anaemia.
Enzymes	Proteins that control metabolic processes and break down foreign substances in the body.

GLOSSARY

Glomerular Filtration Rate (GFR)	Common test for kidney function.
Glomeruli	Set of tiny blood vessels in the nephron of the kidney.
Glomerulonephritis	Inflammation of the glomeruli.
Haemoglobin	Substance in red blood cells that carries oxygen to all parts of the body.
Hypertension	High blood pressure. Uncontrolled hypertension is one of the leading causes of kidney disease.
Insulin	Hormone that helps the body use glucose for energy.
Kidney Transplant	Surgical procedure of placing a kidney from a donor to a recipient.
Nephrologist	Consultant physician who specialises in kidney health.
Nephron	Small filtering unit in the kidney.
Phosphate	Mineral found in the blood and skeleton. People with kidney disease should be careful that their phosphate levels do not get too high.
Polycystic Kidney Disease	Genetic disease where there are multiple cysts in the kidneys. Can be a cause of kidney deterioration or failure.
Potassium	Mineral that is normally present in the blood. Too much or too little can cause problems in the body and people with reduced kidney function should be careful not to eat too many foods that are high in potassium.
Protein	Found naturally in the body and also a class of food - found in meat, fish, eggs, vegetables etc.
Reflux Nephropathy	Kidney condition caused by the backflow of urine from the bladder up the ureter into the kidney.
Sodium	Mineral in the body - most of the sodium we consume is salt. Too much salt in the diet can be harmful for people with reduced kidney function.
Uraemia	Build up of waste in the blood that can cause nausea, vomiting, tiredness and problems with concentration.
Urea	Waste product formed when protein is broken down in the body.
Ureter	Tube that carries urine from the kidneys to the bladder.
Vein	Vessel that carries blood back to the heart.
White Blood Cells	Cells that form part of the immune system.

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MEDICAL SHORTHAND

AAA	abdominal aneurysm
AC	before food
AD	Alzheimer's disease
AE	air entry
AIDS	acquired immunodeficiency syndrome
APD	automatic peritoneal dialysis
ARF	acute renal failure
AS	aortic stenosis
AXR	abdominal X-ray
BBV	blood borne virus
BD	twice daily
B(N)O	bowels (not) open
BP	blood pressure
BS	breath sounds
CAPD	continuous ambulatory peritoneal dialysis
CKD	chronic kidney disease
CRF	chronic renal failure
CN I-XI	cranial nerves 1-12
CP	chest pain
CSU	catheter specimen urine
CT	computed tomography
CVA	cerebrovascular accident
CXR	chest X-ray
D&V	diarrhoea and vomiting
DTP	diphtheria, tetanus, pertussis
DVT	deep vein thrombosis
EDD	estimated date of delivery
EMU	early morning urine
ERSD	end stage renal disease
FBC	full blood count
FHx	family history
GFR	glomerular filtration rate
Hb	haemoglobin
HEP B	Hepatitis B
HEP C	Hepatitis C
Hib	Haemophilus influenzae (b)
HIV	human immunodeficiency virus
HPc	history of Pc
HS	heart sounds
Ht	haematocrit
IVP	intra venous pyelogram
Ix	investigations
JPS	joint position sense
JVP	jugular venous pressure
KUB	kidneys, ureters, & bladder
LFTs	liver function tests

LMP	last menstrual period
LOC	loss of consciousness
LRD	living related donor
LT	light touch
Mane	in the morning
MCS	microscopy, culture & sensitivity
MCV	mean corpuscular volume
MI	myocardial infarction
MMR	measles, mumps, rubella
MRI	magnetic resonance imaging
MRSA	methicillin resistant staphylococcus aureus



KNOW YOUR HOSPITAL...

The following codes are now being used widely by health service professionals:

TUH	Tallaght University Hospital
BH	Beaumont Hospital
CGH	Cavan General Hospital
CUH	Cork University Hospital
UHK	University Hospital Kerry (Tralee)
LUH	Letterkenny University Hospital
MAYO	Mayo General Hospital
MMUH	Mater Misericordiae Hospital
MPUH	Merlin Park University Hospital
MRHT	MRH Tullamore General hospital
UHL	University Hospital Limerick
SGH	Sligo University Hospital
SVUH	St. Vincent's University Hospital
UHW	University Hospital Waterford
MS	multiple sclerosis
MSU	mid-stream urine
N&V	nausea and vomiting
Nocte	at night
NPL	no perception of light
OCp	oral contraceptive pill
OD	once daily
ODQ	on direct questioning
O/e	on examination
OTC	over the counter
Pc	presenting complaint
PD	peritoneal dialysis
PMHx	past medical history
PN	percussion note
PND	paroxysmal nocturnal dyspnoea (waking SOB)
POM	prescription only medicine
PP	peripheral pulses
PR	per rectum
Prn	when required
PSM	pan-systolic murmur
PTA	pancreas transplant alone
PU	passing urine
Qds	four times a day
RBC	red blood count
RRT	renal replacement therapy
RTA	road traffic accident
Rx	treatment, prescription
S/c	sub-cutaneous
SHx	social history
SI	sexual intercourse
SL	sub-lingual
SOA	swelling of ankles
SOB	shortness of breath
SOBAR	SOB at rest
SOBOE	SOB on exertion
SPK	simultaneous pancreas & kidney transplant
STD	sexually transmitted disease
TB	tuberculosis
Tds	three times a day
Tx	Transplant
TIA	transient ischaemic attack
U&E	urea and electrolytes
USA	unstable angina
USS	ultrasound scan
VRE	vancomycin resistant enterococci
WR	Wassermann reaction
X/7	number of days
X/12	number of months
X/52	number of weeks

IKA SUPPORT MAGAZINE



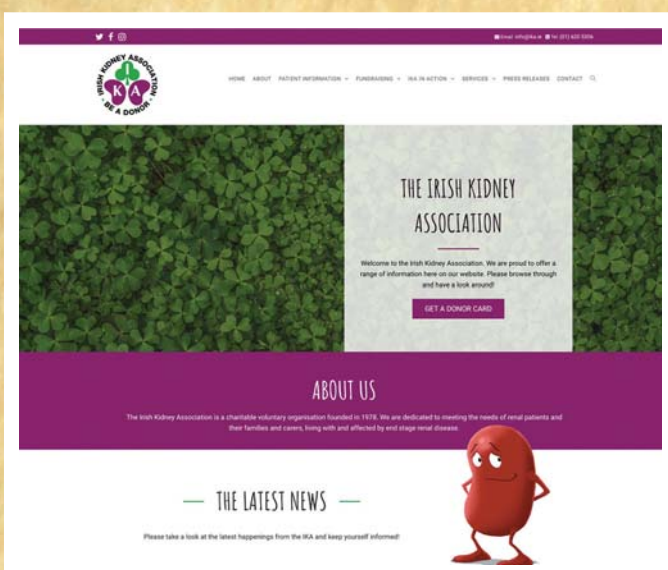
The 'SUPPORT' Magazine is produced four times a year and is posted free to members and people who have requested a copy. Each Haemodialysis Unit receives a quantity of copies of each edition. Local branch news is a favourite of many of the readers. Back-dated editions can be read or printed from the website below.

MULTIMEDIA

www.ika.ie

The IKA website is a valuable source of up-to-date information about renal disease and national and international developments.

We also have many followers on **FACEBOOK** and **TWITTER**



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<https://twitter.com/IrishKidneyAs>



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