

# Kidney Care in Cornwall



## Useful contacts

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Dr G Gentile (via Secretary)	01872 253264
Dr J Louw (via Secretary)	01872 252731
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Dr J Stratton (via Secretary)	01872 252734
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Emma Trebilcock and Susan Durkin, Chronic Kidney Disease Nurse Specialists	01872 252065
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## Introduction

The kidney Unit provides support and information to you about your kidney condition. The aim of this booklet is to answer some of your questions and act as a reminder for you. It may also encourage you to ask more questions, and be helpful to your friends and family who may also want to know more.

Our specialist nurses, doctors, dietitians and support workers are available to help you to understand about your condition.

There is a lot of unregulated information available on the internet. Experiences of kidney problems by others may not apply to you, so be careful what you read or hear elsewhere. If you want to check that information, please do ask.

We hope this booklet answers some of your questions and becomes a useful resource for you.



## **Chronic kidney disease**

One in 10 people in the UK have chronic kidney disease. The word chronic means that the kidney problem has been present for some time. Most people with kidney disease don't know they have a kidney problem.

### **Where are the kidneys and how big are they?**

Your kidneys are positioned in your back, on each side just underneath your ribcage. They are roughly the same size as your fist.

### **What do the kidneys do?**

The kidneys are an important part of the body. They are involved in:

- removing waste products and water
- making blood
- keeping bones healthy.

As kidney disease gets worse some or all of these functions may become a problem. The kidney department can help with all of these things.

### **Symptoms of chronic kidney disease**

Some patients have no symptoms, while others develop symptoms as their kidney function gradually gets worse, such as:

- loss of appetite
- feeling sick (nausea)
- vomiting
- itching
- feeling short of breath
- ankle swelling
- feeling tired
- needing to pass urine at night
- skin discolouration
- bruise easily

most of these symptoms are treatable.

## Blood pressure in people with chronic kidney disease

Studies have shown that people's kidney function gets worse quicker if they have high blood pressure. This is why we focus on good blood pressure control where possible. Ideally, people with chronic kidney disease should have a blood pressure below 140 / 90.

People with diabetes are recommended to have a lower blood pressure, ideally below 130 / 80. This is because people with diabetes and chronic kidney disease are already at higher risk of more serious kidney disease.

## Tablets and medication for people with chronic kidney disease

PLEASE INFORM YOUR KIDNEY DOCTOR OF ALL THE TABLETS YOU TAKE, INCLUDING HERBAL REMEDIES AND NON-PRESCRIPTION DRUGS.

Tablets that people with chronic kidney disease should **avoid**:

### 1. **Anti-inflammatories also known as non steroidal anti-inflammatory drugs or NSAIDS.** These include:

- Ibuprofen
- Nurofen
- Brufen
- Diclofenac/Voltarol
- Naproxen



They are good painkillers but can make kidney problems worse.

The following painkillers do not affect the kidneys:

- Paracetamol
- Co-codamol
- Co-dydramol - can be taken with caution.  
Discuss with your GP or kidney consultant when your kidney function is less than (egfr) 20, as it is likely you will be advised to stop these.



If you are taking Aspirin to protect your heart this is safe.

### 2. **Metformin** (for diabetes). If your kidney function is less than 30% of normal Metformin may build up in your body. If this happens we will recommend that you stop taking it. It might then be necessary to start other treatments for your diabetes.

## The five stages of chronic kidney disease

Chronic kidney disease is categorised into five stages. These are shown in the table below. Ask a member of the team which stage of kidney disease you have.

Stage	Description
1	Normal kidney blood test, with other evidence of kidney damage
2	Slight decrease in kidney function
3a	Moderate decrease in kidney function
3b	
4	Marked decrease in kidney function
5	Advanced decrease in kidney function/kidney failure

## **Diet and lifestyle**

### **Introduction**

Diet plays an important part in the treatment of kidney failure. The advice you are given will suit your particular needs and may change as your kidney condition changes. You should only alter your diet if advised to do so by your dietitian or doctor. Written information and diet sheets can be provided as required.

It is important that you eat well. If at any time your appetite decreases and you find you are losing weight please ask to see a dietitian. There is always a dietitian available to talk to you. An appointment can be made to see the dietitian in clinic or at another agreed time.

If you wish to see a dietitian, at any time, please tell your doctor or the renal specialist nurses. For urgent enquiries, one of the renal dietitians can be contacted on 01872 252409 Monday - Friday.

Relatives, partners or friends are welcome to attend your consultation with the dietitian if you feel this would be useful. Information on eating out, menu planning etc can be discussed to help you continue life as normal.

Eating the right diet can help you stay well when your kidneys are not working properly. You should aim to keep your weight within the recommended healthy range for your height. The dietitian will let you know what this is.

NB Salt - Please avoid salt substitutes such as Lo-Salt and Lo-Salt products as these can be harmful for some kidney patients. Ordinary salt can be used but try to avoid adding at the table.

## Star fruit

Recent research has suggested that star fruit can be poisonous to kidney patients. Don't worry if you have eaten star fruit in the past but we recommend that you avoid it until more is known.



## Smoking

Smoking can kill and may cause lung cancer. It also increases the risk of:

- heart disease
- stroke and other diseases.

Even in non smokers, chronic kidney disease increases the risk of:

- heart attacks
- diseased blood vessels



Therefore continuing to smoke with kidney disease carries an extremely high risk.

Most smokers want to stop smoking. It is the single most important thing a smoker can do to stay in better health. You may find it easier than you thought to stop smoking. There is plenty of help and support available. Your GP can advise you about 'Stop smoking support groups and one-to-one support'.

## Alcohol

Alcohol can be drunk in moderation, but once you are on dialysis it must be counted as part of your normal fluid allowance. Too much alcohol can put your health at serious risk.

## Exercise

Exercise can have a profound effect on health and wellbeing. Taking regular exercise is important. This might involve going swimming, cycling, doing an exercise class or playing a sport, but it also includes everyday things such as gardening, walking, vacuuming and climbing stairs.

Exercise can give you:

- more strength and energy
- improved sleep
- better balance, strength, suppleness and mobility
- stronger bones and muscles
- better weight control
- a sense of achievement
- a chance to make new friends
- help with blood pressure control and cholesterol level.



It can also:

- help relieve tension which will enable you to relax and feel less tense
- be fun.

If you haven't exercised before that does not mean you can't start now. It is important that your exercise programme is designed for you, is enjoyable and will fit into your lifestyle.

Before starting any exercise programme, be sure to check with your doctor.

Helpful contact: Chronic kidney disease clinical nurse specialist  
01872 252065

## **Practical support for you and your family**

### **Prescription charges**

Patients who have to pay for more than four prescription items in three months or 14 items in 12 months may find it cheaper to buy a pre-payment certificate (PPC). Details of the current prescription charge and pre-payment certificate costs are available in leaflet HC12 - Charges and optical voucher values. Details and application forms can be obtained from pharmacies, GP surgeries, libraries and online at [www.dh.gov.uk/helpwithhealthcosts](http://www.dh.gov.uk/helpwithhealthcosts).

**Important** - Some people can get free prescriptions. Check leaflet HC11 to see if you could get free prescriptions before buying a PPC. Usually if you are receiving a means-tested benefit, are over 60 years of age, or have specific medical conditions you may claim assistance.

However, if you have started dialysis, and do not meet the above criteria, you may still be able to qualify for an exemption certificate by completing FP92A which can be obtained from the renal team. It is important to remember that if you have a transplant you may forfeit this entitlement.

### **Outpatient appointments**

If you have to pay to park at the hospital for your appointment and you are receiving a means-tested benefit, you may be entitled to assistance with parking fees and petrol costs provided you bring proof of your entitlement such as a letter from Department of Works & Pensions (DWP). Assistance is also available if you use public transport and can supply proof of payments and entitlement.

The application form is available in the out patients department and must be completed there. The form (and proof letter) then needs to be taken to the General Office between 09.30 - 17.00 Mon to Friday for payment.

If you have travel difficulties, Age Concern (TAP) can be contacted to organise a reduced fee-paying taxi service.

## State Benefits

There are some benefits that you may be entitled to if you are experiencing financial, or employment problems due to your renal impairment. For individual advice contact Jobcentre Plus or Citizens Advice Bureaux listed in the local telephone directory.

## Useful websites, telephone numbers and addresses

Andrea Cabanig, Renal Specialist Nurse  
Renal Unit  
Royal Cornwall Hospital  
Truro  
Cornwall  
TR1 3LJ  
01872 252081



For advice on benefits you may be entitled to and help with the application process, support and advice for you and your family.

Kidney Care UK  
Tel: 01420 541424  
[www.kidneycareuk.org](http://www.kidneycareuk.org)

Provides support, advice, counselling and financial help with kidney patients and their families.



Patient Knows Best UK - to access your latest blood results.  
[www.patientknowsbest.com/](http://www.patientknowsbest.com/)

Patients with access to the internet can also access a confidential website called **Patient Knows Best**. This site allows people with kidney disease to look at their own kidney blood results. If this interests you please ask a member of the kidney team for more details.

Please ask your kidney team about details of our Renal Patient Support Group.

## **Renal anaemia caused by chronic kidney disease**

### **What is renal anaemia?**

Renal anaemia is very common among people with chronic kidney disease. Anaemia occurs when there are not enough red blood cells to carry oxygen from the lungs to places where it's needed. Anaemia can be caused by blood loss and/or blood cells becoming damaged.

### **What is erythropoietin?**

Erythropoietin (EPO) is a hormone produced by the kidneys. Damaged kidneys are unable to produce enough quantities of this hormone. EPO travels in your blood from your kidneys to your bone marrow constantly stimulating it to make red blood cells. When your kidneys do not work properly not enough EPO is made. This means that your bone marrow stops making enough red blood cells. When this happens the number of red blood cells declines and you become anaemic.

### **How will I know that I am anaemic?**

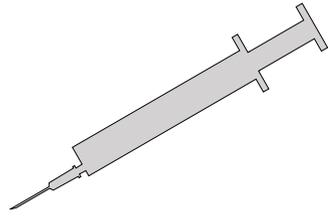
Anaemia is usually diagnosed as part of routine blood tests. Symptoms of anaemia may include:

- a lack of energy and feeling tired
- breathlessness on exertion
- mood changes
- disturbed sleep patterns
- impaired ability to concentrate for long periods of time
- sexual function may also be impaired.

### **How can renal anaemia be treated?**

In the past blood transfusion was the only treatment available to treat renal anaemia. More recently drugs which act like the natural hormone erythropoietin have been developed. These drugs are given by injections under the skin. The dose will be worked out taking your weight into consideration and may be changed as your anaemia improves.

Blood tests are regularly taken to measure the quantity of your red blood cells and the level of iron in your blood. Your body needs iron to make red blood cells. If there is not enough iron in your blood you will need extra in the form of iron infusions.



### **Are there any side effects with these drugs?**

Most people have no side effects from taking EPO injections, but some patients may experience:

- headaches
- a rise in blood pressure
- discomfort in the area where they had the injection
- a small number of patients suffer flu like symptoms.

Some people notice a metallic taste in their mouth for a short time when they are given intravenous iron. Less common side effects include:

- a drop in blood pressure
- injection site reactions.

If you have any worries or concerns, tell your nurse or doctor.

### **How quickly will I feel better?**

The improvement in your anaemia symptoms will be gradual. It takes a while for your body to make enough red blood cells to replace the ones it has lost so you may not feel any better for about four to six weeks.

Helpful contact: Lead nurse in renal anaemia 01872 253499

## Fluid management for people with chronic kidney disease

The body is made up of 75% water. The kidneys are involved in removing water and salt from the body. If you have chronic kidney disease it is important to continue to drink a normal amount of water.

If too much water builds up in your body you may notice:

- a rise in your blood pressure
- ankle swelling
- worsening shortness of breath
- being unable to lie flat.

Not everyone with kidney failure develops these symptoms. If you do notice these symptoms it is important to mention it to one of the kidney team. You might be prescribed water tablets (diuretics) to help remove some of this extra water.



Reducing salt in your diet can also help to reduce water building up because salt makes the body hold on to water. You might be asked to weigh yourself once a week. This is a good way of measuring how much water is in your body.

## Renal bone disease

Healthy kidneys help to keep our bones strong. People with chronic kidney disease can develop weakened and thinned bones because their kidneys are not working normally.

The kidneys are involved in calcium, phosphate and vitamin D chemistry. Your kidney consultant might prescribe you activated vitamin D, or other tablets to help reduce this bone thinning.



## Jargon busting

Access	A way of getting to the bloodstream to perform dialysis
Anaemia	A deficiency of red blood cells and haemoglobin
APD	Automated peritoneal dialysis
Biopsy	Removal of a small piece of tissue from an organ
CAPD	Continuous ambulatory peritoneal dialysis
Creatinine	Waste product created by muscles. An indicator of how well your kidneys are performing
Dialysis	An artificial method of removing waste products from the body
EPO erythropoietin	A hormone produced by the kidneys that promotes the formation of red blood cells
Fistula	The joining of a vein and artery just under the skin, usually on the forearm. This makes the vein swell allowing needles to be inserted and removed after each treatment
Hypotension	Low blood pressure
Hypertension	High blood pressure
Peritoneum	Membrane that lines the abdomen and acts as a filter for dialysis with APD/CAPD
Peritonitis	An inflammation of the peritoneum as a result of an infection
Renal	Kidney
Tenckhoff	A catheter used for APD/CAPD dialysis
Urea	A waste product created by the breakdown of proteins

## **My kidney care plan**

### **Preparing for your hospital appointment**

Whenever you see a healthcare professional – in a hospital, clinic or GP surgery – there are things you can do beforehand to make sure you get the most from the appointment.

- Write down your most important questions.
- List or bring all your medicines and pills – including vitamins and supplements.
- Write down details of your symptoms, including when they started and what makes them better or worse.
- Ask your hospital or surgery for an interpreter or communication support, if needed.
- Ask a friend or family member to come with you, if you like.

### **During your appointment**

- Be clear about the symptoms you're experiencing, and be honest – they'll have heard it all before, so there's no need to be embarrassed
- Don't be afraid to ask if you don't understand. For example, 'Can you say that again? I still don't understand.'?
- If you don't understand any words, ask for them to be written down and explained.
- Ask a family member or friend to take notes.
- Ask for printed information explaining any procedures or background on your condition

### **Before you leave your appointment**

Check:

- you've covered everything on your list
- you understand, for example 'Can I just check I understood what you said?'
- you know what should happen next – and when. Write it down.

Ask:

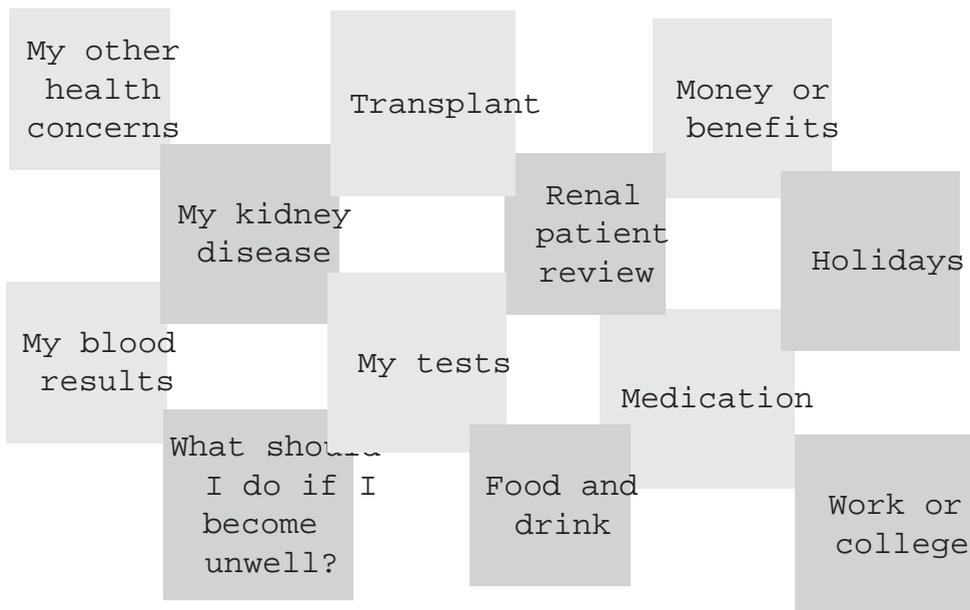
- who to contact if you have any more problems or questions
- about support groups and where to go for reliable information
- for copies of letters written about you – you are entitled to see these.

### **After your appointment, don't forget the following**

- Write down what you discussed and what happens next. Keep your notes.
- Book any tests that you can and put the dates in your diary.

Ask:

- 'What happens if I'm not sent my appointment details?'





## My care plan

Your care plan can be filled in at any time. It will list the things that are currently important in your care from the renal service. It might include things that are working well, and goals that you and your renal team are working towards. It might also take into account things you want to change, or any issues and concerns you may have.

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What might help me?

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What do I need my care team to do?

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What do I need to do?

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I would like copies of any letters you send to my GP - please discuss during next clinic visit.

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If you would like this leaflet in large print, braille, audio version or in another language, please contact the General Office on 01872 252690

