

Living with Kidney Failure
A guide for patients and their families

York Renal Team

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Introduction

The aim of this guide is to provide you with information about your kidney failure. It won't tell you everything you want to know about the experiences and treatment you will have, but we hope it will be a useful starting point for you and your family.

It has been put together by members of the York Renal Team. The Renal Team is made up of many professionals who are here to help you. You may find it bewildering at first trying to work out who does what in the team, which is made up of consultant nephrologists (kidney specialists), junior medical staff, nurses, reception and secretarial staff, dietitians, a pharmacist, clinical psychologists and social workers. The main thing to remember, though, is that as a team we want to provide you with all the help and information you need to live with kidney failure. As you read through this guide, you may come across words that are new to you. The Glossary of Terms (starting on p. 49) should provide you with the explanations you need. If the word you're looking for isn't in the Glossary, then just ask a member of the Renal Team what it means.

Frequently asked questions (FAQs)

Written by people with kidney failure, for people with kidney failure.

What do my kidneys do?

The main function of kidneys is to remove waste from your blood and produce urine. Kidneys also balance many important chemicals in your body.

See Chapter 1 for more details.

Have I really got kidney failure? I feel ok?

Many people with kidney failure do not notice that they feel any different in the early stages. However, blood tests will show that there is a problem with your kidneys.

See Chapter 2 for more details.

Why have my kidneys failed?

There are a number of reasons why kidneys fail. It can be genetic, or as a result of other illnesses or infections. Sometimes there is no definite cause.

See Chapter 2 for more details.

What treatments are there?

There are a number of treatments, including diet, medication, dialysis, transplant and conservative treatment.

See Chapter 3 for more details.

What is dialysis?

There are two types of dialysis. In haemodialysis, your blood is passed through a machine to take out waste and water. In peritoneal dialysis, fluid is put into your tummy, where it removes the waste which is then drained out.

See Chapter 3 for more details.

What is 'conservative treatment'?

Sometimes, the negative aspects of dialysis outweigh the benefits, and people with difficult health problems may choose conservative treatment instead.

See Chapter 3 for more details.

Will I be able to get a transplant?

It may be possible to receive a transplant from a live donor, who could be either related (for example a brother) or unrelated (such as your partner), or from the national kidney transplant waiting list. You have to be fit enough to have a transplant. Whether you receive a kidney transplant from the national waiting list largely depends on whether a suitable donor match becomes available.

See Chapter 3 for more details.

Will kidney failure affect my life?

Yes, there will be some changes to your diet and lifestyle, and some of your time will have to be devoted to your treatment. However, many patients find that over time they adapt well to these changes.

See Chapters 4 and 5 for more details.

Will I still be able to work?

Yes, in most cases. Carrying on working can bring many positive benefits, although you may need extra time off for hospital appointments and blood tests.

See Chapter 5 for more details.

Will I still be able to go on holiday?

Yes, although it will require a little more forward planning and your choice of destinations may be more limited. Your Renal Team can help with this.

See Chapter 5 for more details.

Will kidney failure affect my sex life?

Many people with kidney failure experience a reduced sex drive. It is important to discuss this with your partner. If either of you needs help, talk to a member of your Renal Team.

See Chapter 5 for more details.

How will it affect my partner and my family?

Many partners and family members have fears about the future. Some experience a sense of loss when they think about the limitations that living with kidney failure brings. It is important to talk to family and friends about your kidney failure and how the symptoms affect you. If you find this difficult, your Renal Team are there to help.

See Chapters 6 and 7 for more details.

Is there anything I can do to help myself?

Learning as much as you can about your condition may help to lessen any concerns, anxieties or fears that you might have. There are many good books and organisations that can provide information.

See Chapter 8 for more details.

How long will I live?

This varies a lot, depending on your age and any other medical conditions you have. Your consultant can tell you more about this. Many kidney patients live long and fulfilling lives. Focusing on hobbies, work or other new challenges instead of your kidney failure can be very helpful.

See Chapters 5 and 6 for more details.

1 What kidneys do?

Most people have two kidneys which are located in the small of the back, each about the size of a fist. Their job is to constantly filter blood, removing excess water and the waste products that build up in the body by producing urine.

Other functions of the kidneys include:

- balancing chemicals such as potassium and sodium in the blood
- regulating the acid balance in the blood
- producing hormones, for example erythropoietin which helps the bone marrow make red blood cells
- producing vitamin D which ensures that bones are strong and healthy
- controlling blood pressure.

Even if the kidneys begin to fail, they can still keep a person healthy. However, as this failure increases, it can affect the body in many ways.

2 What is kidney failure?

If you have 'severe' kidney failure, it means that your kidneys are working at less than a fifth of normal function.

Having kidney failure will not necessarily affect your urine output. Urine quantity and appearance may be normal even in severe kidney failure.

Kidney failure can happen to anyone at any age. According to the National Kidney Research Fund (now Kidney Research UK) in 2001 there were approximately 32,000 people in the UK receiving treatment for kidney failure and by 2012 there were approximately 41,000 people receiving treatment for kidney failure (NHS Choices 2012).

What causes kidney failure?

There are many causes of kidney failure, including:

- diabetes
- high blood pressure
- inflammation
- blockage to the urine flow
- chronic infection.

Sometimes though, we never find the exact cause of a person's kidney failure.

If we do know the cause of your kidney failure, we may need to do tests to decide if we can treat that cause.

Whatever the cause, it is always extremely important to control blood pressure carefully to prevent additional kidney damage.

The Renal Team can give you more information about what caused your kidney failure.

How might kidney failure make me feel?

There are a wide variety of symptoms that people with kidney failure may experience. These include:

- tiredness
- loss of appetite
- nausea and sickness
- altered taste sensation
- cloudier thought processes
- loss of libido
- restless legs
- itching
- shortness of breath.

The Renal Team can help with many of these symptoms, so it is important for you to tell us how you are feeling.

What problems can occur?

If you have kidney failure, you are at risk of developing certain problems, including:

- chemical build-up in the body
- fluid imbalance in the body
- anaemia
- bone disease
- blood vessel damage (leading to, for example, heart attack or stroke).

We will look at how each of these may affect you, and how it can be treated, below.

Chemical build-up

As kidneys fail they are unable to get rid of various chemicals in the body. These chemicals then build up, causing different sorts of problems. For example, too much potassium may cause heart rhythm problems.

To begin with, the chemical build-up can be treated by dietary changes and medication alone, but eventually dialysis is needed as well, to keep these chemicals to an acceptable level.

We may also need to treat anaemia with iron replacement therapy, which is given either in the form of iron tablets or by an injection of iron. This is done in hospital via an injection into the vein, and takes about 15 minutes.

You can find further information about treatment for anaemia in the drugs section of this

Fluid imbalance

The kidneys maintain a normal balance of salt and water in the body. As kidneys fail, it is very common for too much salt and water to build up in the body. This can cause swollen ankles (ankle oedema), breathlessness and high blood pressure. Diet, (water tablets) diuretics and dialysis are used to keep fluid balance in control. Sometimes, particularly during other illnesses such as diarrhoea and vomiting, the body becomes short of salt and water. This can lead to low blood pressure, causing the kidneys to work less well.

Anaemia

People with anaemia have a shortage of red blood cells. Normal kidneys make a chemical called erythropoietin (EPO). This is released into the circulation and travels to the bone marrow where it enables the marrow to make red blood cells. As kidneys fail they make less EPO, and so anaemia develops.

We can give patients artificial EPO that corrects the anaemia. All patients with kidney failure are offered this treatment if they need it.

We may also need to treat anaemia with iron replacement therapy, which is given either in the form of iron tablets or by an injection of iron. This is done in hospital via an injection into the vein, and takes about 15 minutes.

You can find further information about treatment for anaemia in the drugs section of this guide (Chapter 9).

Bone disease

Bone disease is caused by high phosphate levels and by low calcium and vitamin D levels. It can be prevented by dietary changes (phosphate restriction – your dietitian will explain more about this), and by drug treatments (e.g. calcium supplements, phosphate binders and alfacalcidol).

Blood vessel damage

Blood vessel damage can lead to heart disease or stroke. The damage is caused mainly by smoking, high blood pressure, high calcium and phosphate levels and high cholesterol levels. It is important to try and stop smoking so that you reduce blood vessel damage. Nicotine replacement treatment may be helpful in the process of quitting. The other factors affecting blood vessels can be dealt with by medication and diet.

3 Treating kidney failure

Your kidney failure will be treated by a combination of the following:

- diet
- medication
- kidney replacement treatment (i.e. dialysis or transplantation).
- conservative care.

We will look at each of these in turn.

Diet

'First need in reform of hospital management? That's easy! Death of all dietitians and resurrection of a French Chef.'

(Martin H. Fisher, 1879–1962)

By the time you have had a few discussions with the renal dietitian, this may well be a sentiment that you share!

We cannot avoid the fact that kidney failure will mean making a number of changes to your diet. You need to be aware that these changes are an important part of your treatment. We find that this is probably the part of kidney care where people get the most conflicting and least 'scientific' information. People often get advice from friends, the newspaper, magazines, television or someone at the gym. This advice is often wrong! It is the job of the renal dietitian to make the renal diet as understandable and as tolerable for you as possible, and above all to ensure that it fits in with your lifestyle, so that you can continue to enjoy food and eating.

Why is diet important?

As we have already mentioned, one of the main functions of the kidneys is to get rid of waste products from the blood. Many of these waste products come from the food we eat, and if your kidneys are not working properly they build up in your blood making you feel unwell. The treatment that you may have, such as dialysis, will remove some of these waste products. The right diet is important to help reduce the amount of waste that is produced and keep you feeling fit and well. Some changes to your diet will be made quite early on, probably well before dialysis becomes necessary. The diet may change several times over the months or years. This is not because the dietitian keeps getting it wrong, but because your dietary needs change as your condition changes.

As well as advising you on any necessary changes to your diet, the renal dietitian also wants to make sure that you continue to eat an adequate diet and stay well nourished. To help us monitor how well nourished you are, the dietitian may do some simple tests, such as taking measurements on your upper arm, when you come to clinic. This is part of a nutritional assessment.

Remember that you are unique! Your diet will be tailored to suit your needs, and we will only advise you to change your diet if and when it becomes necessary. Do not be tempted to make changes to your diet that are not required, as this can mean that you might be missing out on some nutrients and make life more difficult than it needs to be. You should not feel that you have to eat different meals to the rest of the family. And you will be given advice on how to plan ahead and make suitable menu choices, so that you can continue to enjoy eating out.

What dietary changes may be necessary?

The dietary changes you are most likely to need to make concern:

- salt
- fluids
- phosphates
- potassium
- protein.

Salt

You should start to reduce your salt intake as soon as possible. This will help to control your blood pressure and the amount of fluid in your body.

When you require dialysis, we will probably advise you at some stage to reduce the amount of fluid in your diet. Restricting your salt intake will help with this by preventing you becoming too thirsty. You should stop adding salt to food at the table and preferably avoid using any in cooking. It is usually a good idea to steer clear of salt substitutes such as Losalt or Solo too, since these can also make you thirsty and they contain a lot of potassium, which you may need to avoid.

Some foods have a high salt content. Your dietitian will tell you how much or how often you can eat these.

Fluids

If we advise you to follow a fluid restriction you would need to keep a check on the number of drinks you have each day.

Your restriction would also include any foods which have a high fluid content. We will advise you on how much fluid there is in each of these foods and also explain how to count the amount of fluid in your drinks.

In Section 4 we will look at fluid balance in more detail.

Phosphates

The kidneys normally control the amount of phosphates in your blood. If the phosphate levels get too high you might experience some itching, but more importantly this can lead to bone problems and a build-up of phosphate and calcium deposits in your blood vessels. So it is important that we treat high blood phosphate levels. Diet has a major part to play in this.

Your dietitian will give you information about how to cut down on high phosphate foods when it becomes necessary.

Potassium

High levels of potassium in your blood can cause muscular weakness or heart problems. If your levels are high you will need to reduce the amount of potassium in your diet. Your dietitian will tell you more about this and about high potassium foods to avoid, if it becomes necessary.

Protein

Before you start dialysis we may advise you to avoid eating excessive amounts of protein foods such as meat, fish and dairy produce. This is because protein foods create a lot of waste that your kidneys cannot get rid of effectively. It is always important to eat the right amount of protein foods – either too much or too little

can cause problems. The renal dietitian will advise you on how to make the best changes to your intake.

If you go onto dialysis, you will have to go back to eating more protein again so that you stay well nourished.

Healthy eating

As much as possible we will advise you to continue with the general principles of healthy eating, which are: low fat, low sugar, low salt and high fibre. Sometimes if you are losing weight or not eating well, it may be necessary to break a few of these rules in order to make sure your dietary intake is always adequate.

This can all sound very daunting and confusing. Making changes to your diet is not always easy but you will get lots of help, advice and support from the renal dietitian. Despite having to restrict some foods, the most important thing is to keep your diet balanced and healthy so that you stay well nourished.

Remember that everyone is individual and different. You may not have the same dietary restrictions as someone else with kidney failure. If you are unsure about any part of your diet, or if you get lots of different or conflicting advice from different people, the best thing to do is check it out with your dietitian.

Diet after transplantation

A successful transplant should mean that you can start to enjoy a normal diet, free from many restrictions. We will still advise you though to follow the usual principles of healthy eating. You should aim to eat a diet which is low in fat and sugar, and high in fibre. It would also benefit you to continue avoiding added salt. You will need to be careful to follow sensible food hygiene and food safety advice and you may need to cut out a few foods which affect some of the transplant medication. Some people find that they gain weight after a transplant, probably due to a combination of eating well and the effects of some tablets such as steroids. If you are concerned about weight gain, the renal dietitian can give you more advice.

Medication

Most patients with kidney failure will have to take a number of essential drugs.

These are to correct the effects of the kidneys not working properly.

We realise that for some people it is difficult to take so many different tablets and capsules. However, it is very important that you take all your medication as prescribed and follow the advice given to you by the Renal Team. If you are having problems taking your medication, for whatever reason, please let the nursing staff, pharmacist or doctor know so that we can try to help you.

Many drugs can now be bought at the pharmacy or supermarket without a prescription. Some of these drugs may not be safe for people with kidney failure. These can include things such as cod liver oil and some herbal remedies. You also need to take care with some types of painkillers (especially ibuprofen) and some indigestion remedies.

It is very important to check with your renal doctor or pharmacist before taking anything that is not prescribed. If a GP prescribes something for you, please make sure they are aware of your kidney problems.

If you have any questions about any medicines, ones you have bought yourself or ones that have been prescribed for you, please let us know and we will check whether they are safe for you to take.

Section 9 of this guide lists the drugs most commonly taken by people with kidney failure. It is there to help you understand what you have been prescribed, and why. If you have any questions about these or any other medication you are taking, the Renal Team pharmacist will be happy to talk with you.

People with kidney disease are not exempt from prescription charges, unless they are receiving renal dialysis patients through permanent haemodialysis or peritoneal dialysis access. You may already be exempt from prescription charges for another reason, for example if you are over 65 years old, or have another medical condition such as diabetes. If you take more than 2 regular medications and pay for your prescriptions, it might be cheaper to buy a pre-payment prescription certificate. Application forms for these certificates are available at a pharmacy. Alternatively you can check the website at www.nhsbsa.nhs.uk/ppc for more information or you can phone 0300 330 1341 to order a prepayment certificate by debit or credit card.

The rules we have outlined here about prescription charges and pre-payment certificates may change. This information is correct at the time of writing, but it would be wise to ask your pharmacist what the current rules are.

Kidney replacement treatments

There are two types of kidney replacement treatment:

- dialysis
- transplantation.

We will look at each of these in turn.

Dialysis

Dialysis removes waste products and excess fluids from the blood, and restores some important chemicals like calcium and bicarbonate.

There are two kinds of dialysis:

- haemodialysis (HD)
- peritoneal dialysis (PD).

Haemodialysis mainly takes place in a hospital or satellite unit where you can choose to take part in your own care, or at home after you have had plenty of support and training. Peritoneal dialysis is done by yourself at home. Let's look at how each type of dialysis works (you will get much more information about dialysis if you need to make a choice between one of these treatments).

Haemodialysis

In haemodialysis your blood is passed through a dialysis machine and then returned to you. A treatment session usually lasts four hours and needs to be repeated at least three times a week. Taking blood from you and returning it requires vascular access (access to the bloodstream) preferably via an arteriovenous fistula. To make the arteriovenous fistula you will have to have an operation, usually under local anaesthetic. The operation involves joining an artery and a vein together at your wrist or elbow. This needs to be done a few months before dialysis starts, to allow the vein to get big enough to use for dialysis. If you do not have an arteriovenous fistula you will need a temporary plastic tube (a

catheter) placed in a vein in your neck or groin. This is usually done under local anaesthetic.

Shared and self haemodialysis care

Finding out you have kidney disease and need dialysis can come as a real shock, and some people may feel a loss of control over their lives. Many people feel that haemodialysis should be the job of professionals and would rather leave it to them. However, increasing numbers of patients are finding that by taking part in some aspects of their treatment, they are able to feel more in control again. Shared haemodialysis care involves working closely with the nurses in the dialysis unit and learning how to carry out aspects of your dialysis. For some people, this may mean taking their own weight and blood pressure and for others, preparing the dialysis machine. Some patients prefer to manage all aspects of their dialysis care. This can be done in the dialysis unit, a 'self care' unit or at home. Training and support will be given to help you carry out as much or as little of your care as you wish. If you are interested in shared or self haemodialysis, please talk with your consultant and / or nurse involved in your care.

Peritoneal dialysis

In peritoneal dialysis, dialysis fluid is put in your peritoneal (abdominal) cavity through a flexible plastic tube (a catheter) and it is left there for about six hours before you drain it out and exchange it for some fresh fluid. This exchange is something you do yourself. It is quite easy to do, using plastic bags of fluid and tubing that are delivered to your home. You will need to have an operation to place the tube in the wall of your abdomen. This will usually be done two or three weeks before the dialysis starts. Each exchange takes about 20–30 minutes, and during that time you can do other things like read or watch TV. As there is always dialysis fluid inside your abdomen, dialysis is going on all the time. This is why it is called continuous ambulatory peritoneal dialysis (CAPD). You will be trained how to do this at home and sometimes other family members may wish to be involved.

Alternatively it may be possible to use a machine to do automated peritoneal dialysis (APD). This is done at night while you are asleep. If you choose APD, then as with CAPD, you will be trained how to use the machine at home. You will learn how to connect yourself to the machine before you go to bed and disconnect yourself in the morning. This type of dialysis is available to most patients after discussion with the Renal Team.

If you think you will struggle setting up the APD machine and lifting bags of dialysis fluid, Assisted APD is available. A trained assistant will come to your home daily and set up the machine for you.

Haemodialysis or peritoneal dialysis?

Haemodialysis and peritoneal dialysis each have advantages and disadvantages. For many people either treatment would be possible, but one may be more suitable for medical reasons. You will probably be able to choose the form of dialysis that you prefer in discussion with the medical and nursing staff. It is best to make the decision well in advance of dialysis being needed so that the

necessary operation can be done in good time. Switching from one treatment to another is usually possible if there are problems.

You will be offered a home visit from a renal specialist nurse who can discuss these options with you and with your family if you wish. You will also be offered the opportunity of visiting the renal unit and being introduced to other patients on dialysis. Many people find this helpful.

Renal transplantation

For some people the best form of kidney replacement treatment is a kidney transplant, which may come from someone who has died (a deceased donor) or from a live donor who may be related (for example a brother), or genetically unrelated (such as your partner).

You are likely to feel much better with a kidney transplant than you do on dialysis, but there are some points that you should remember:

- You need to be fit enough to undergo the transplant operation.
- You will need medicines called antirejection treatment to prevent your body from destroying the transplant. You will need to take this medicine as long as the kidney is working and these medicines are likely to have some side-effects.
- Around 90% of kidney transplants are still working one year after they have been put in, but after ten years the figure is only about 60%. Even if your kidney fails after two or three years, though, you will still have had a benefit in terms of your quality of life and the general effects on your body of having had a break from dialysis.
- When you are on the national transplant waiting list you may have a short or a long wait, as deceased donor kidneys are allocated according to matching and it is a matter of chance as to whether or not a match comes up for you.
- Some people on the transplant waiting list may never be offered a transplant because factors in their blood or their tissue type make it impossible to find a kidney that will not be rejected.
- Kidney donation from a living donor allows more control over when the transplant operation will occur. The donor needs to be fit and there are a number of medical, administrative and legal checks to be done before a transplant can go ahead.
- If a transplanted kidney fails, you have to return to dialysis. The medical staff would discuss the option of another transplant with you, and if it's appropriate, your name would be put back on the transplant waiting list.

Choosing not to dialyse: the conservative treatment option

For most people dialysis is a life-prolonging treatment, but this is not always the case. After careful thought and discussion with the Renal Team, some people decide that dialysis is not the best treatment for them. Instead they choose to have their symptoms managed using conservative treatment. For these people, the negative aspects associated with dialysis outweigh the benefits, and they choose to live their life without the disruption to their daily routine caused by dialysis treatment.

Conservative care involves managing the symptoms that kidney failure causes. Symptoms such as swollen ankles, breathlessness, itching and nausea can be helped by medication. Decreasing appetite is also a consequence of kidney failure and while there is no specific treatment for it, a dietetic review by the renal dietitian can often help both you and your carer. Anaemia, caused by kidney failure, can be treated with injections.

Choosing which treatment option is right for you can be difficult. Family members may have a different view and discussions are not always easy. The Renal Team is here to help and support you and your family during this time.

Before you make your decision, your renal consultant will have discussed with you what your options are. You will be offered a home visit with the renal specialist nurse and/or the renal social worker. You may wish to have your family or a friend at this meeting.

The news that your kidneys are failing, and all the information that comes with this, can make this a confusing and worrying time. We will try to give you as much information as you need to make an informed choice about the best and most appropriate treatment option for you. We will review your decision with you regularly and we aim to act at all times in accordance with your wishes.

If you do choose to have conservative treatment rather than dialysis, you will continue to be looked after by your GP and district nurses, in addition to the Renal Team. The specialist renal nurse and the renal social worker can continue to see you and your family at home to ensure that all possible help and assistance is provided. The Macmillan Nursing service also works with the Renal Team to offer support to you and your family.

Deciding not to have dialysis does not necessarily mean you will die of kidney failure. In fact most people who choose not to have dialysis die of other illnesses.

If your kidney function gets worse

If your kidney function does deteriorate, then you will begin to feel more tired, have less energy and perhaps feel unable to carry on with some of your normal daily activities. Some of the symptoms mentioned earlier such as itching, loss of appetite, nausea and breathlessness may become more of a problem as your kidneys get worse. Your medication will need to be reviewed to control these as much as possible. We have written a leaflet for patients and their families called *Treating the Symptoms of Kidney Failure*, which you may find useful.

As your health gradually deteriorates, you may need help with daily activities and personal care. Your GP, district nurses, social worker and renal specialist nurse will work together to ensure you receive the care and support you need.

Thinking about dying can be a difficult, sad and confusing time for patients and their families. Some patients have clear ideas about where they wish to die and what help and support they need from their family and health professionals. The Renal Team can help you document your wishes in an Advance Care Plan, but others do not wish to discuss this. The Renal Team will be available to support you and your family at this time and will be sensitive to any spiritual and cultural needs you may have.

4.Fluid balance and blood pressure control

One of the big problems for people on dialysis is keeping their fluid in balance. Any fluid that goes in must come out. Fluid balance was discussed briefly in Section 3. In this section we will look at it in more detail.

Water and salt balance

Healthy kidneys are very important as they keep control of the amount of salt and water in the body. As kidneys fail, salt and water are retained. This can lead to an increase in blood pressure. In more severe cases fluid can build up in the legs (ankle oedema) or in the lungs (pulmonary oedema), where it causes shortness of breath. Over a long period of time the heart muscle can also be damaged, leading to heart failure.

How much can I drink?

Once you begin dialysis you will not usually be able to drink as much as you like and you will need to restrict salt intake because of its effect on blood pressure. The amount you can drink is dependent on which form of treatment you are on and will be individually assessed.

If you are on peritoneal dialysis, your fluid intake will be assessed on how much urine you pass and how well fluid is removed by the dialysis process.

If you are on haemodialysis, you will be given a fluid restriction which takes into account how much urine you pass and whether you have had blood pressure or fluid removal problems. For example, if you pass no urine, a typical fluid restriction would be 1–1.5 litres per day. This will result in a fluid gain of up to 1 litre (= 1 kg) per day. To help control blood pressure and to avoid heart problems in the future, you should try to limit fluid weight gains to a maximum of 2 litres (= 2 kg) for the two-day dialysis gap, and 2.5 litres (= 2.5 kg) for the three-day gap. Remember that your fluid restriction will include both drinks and 'wet foods' like custard, yoghurt and gravy.

Will I feel thirsty?

Many people find trying to stick to a fluid restriction difficult because they often feel thirsty. You will feel more thirsty if you have a high salt intake, which is another reason why you should try to limit salt in your diet. The renal dietitian will be happy to discuss this with you.

Why is my blood pressure important?

High blood pressure can damage blood vessels, the heart muscle, the brain and the kidneys. Kidney failure causes high blood pressure, and high blood pressure makes kidney failure worse.

As many as eight out of every ten dialysis patients have high blood pressure. We will discuss your ideal blood pressure with you. In general it is related to your age.

How can I control my blood pressure?

As we have discussed, the two most important ways of controlling your blood pressure are:

- reducing your salt intake
- restricting the amount of fluid in your body.

You may also need to take tablets. Section 9 looks at some of the drugs that are prescribed to control blood pressure.

5 Life on dialysis

Being on dialysis will influence many aspects of your life, and there may be adjustments you need to make. We have already looked at changes you may have to make to what you eat and drink. In this section we will be looking at how dialysis may affect the following:

- work
- holidays
- insurance and mortgages
- sex and fertility
- exercise
- smoking
- alcohol
- life expectancy.

Please remember that if you have any concerns or queries about these or any other areas, then talk to a member of the Renal Team about them.

Work

Many people starting dialysis will be worried about their ability to work. There is no specific reason why a person on dialysis should not be able to continue working or obtain suitable employment, provided that they feel physically well enough.

Working can have positive effects on both your physical and your psychological well-being.

If you need advice about your work, or wish to apply for employment, then the Renal Team will help you in every way possible. We can also direct you to agencies that offer more specialised help with employment and training, and your local Jobcentre has a disability employment adviser who may be able to help or signpost you to other support.

Driving

Most people on dialysis continue to drive if they feel well enough. You must inform the DVLA and your car insurers of changes to your health, such as being diagnosed with kidney failure, or starting dialysis.

Holidays

Having kidney failure does not have to stop you going on holiday – in this country or abroad! Just like anyone else, you'll find a holiday does you good.

If you are on a low income the renal social workers may be able to access a grant for you from the British Kidney Patient Association (BKPA).

The only thing to bear in mind is that you will need to make special arrangements so you can continue your dialysis during the holiday.

It is important that you let the nursing staff know as soon as possible when you are thinking about going on holiday. They will be able to give you assistance and advice about making your arrangements. Before you book your holiday, discuss your plans with them to ensure that dialysis facilities are available at the place(s) you are going, and at the times you will need them. An organisation is Dialysis Freedom, whose primary aim is to help to improve the quality of life for dialysis

patients in the UK by providing access to dialysis away from home in the UK via the UK Dialysis Swap Scheme. www.dialysisfreedom.co.uk; they also have a Facebook page.

Some people find it difficult to get holiday insurance. If you have any problems, let us know. We may be able to assist you with the names of companies to approach.

Insurance and mortgages

If you want to take out a new life or employment insurance policy, you will have to declare your kidney failure. The kidney patient associations listed in Section 8 have details of insurance companies that can provide suitable policies. If you are generally well apart from your kidney failure, you should be able to get a mortgage.

Sex and fertility

Many men and women with kidney failure have a reduced sex drive (libido). This is due to both physical and psychological factors.

Many men on dialysis suffer from lack of sex drive and from an inability to obtain or maintain an erection. There are a group of drugs such as Sildenafil (Viagra) that can work for men on dialysis although they are not suitable for everyone.

If you are having problems, discuss them with your partner, who may not understand the effects of kidney failure on sex drive.

The Renal Team do understand that this might be difficult to talk about, but we may be able to help. We hope you will feel you can discuss it with us.

Changes in women's hormone levels mean they may experience changes in their usual menstrual cycle, or their periods may stop altogether. It is very unusual for women on dialysis to become pregnant. Pregnancy has many potential risks for women on dialysis and we would advise you to avoid becoming pregnant. This means using appropriate contraception. Women with kidney failure can use the same types of contraception as women with normal kidney function. You can get advice on contraception from your GP or Family Planning Clinic, or you can discuss the matter with members of the Renal Team.

Exercise

Regular exercise is good for you. It helps to maintain fitness, lower blood pressure and reduce the risk of heart problems and it also improves your general feeling of well-being. If you have any concerns about taking exercise, speak to a member of the Renal Team.

Smoking is a major cause of illness in the general population. Around 50% of smokers die of a smoking-related disease. Most people think of lung cancer and chronic bronchitis in connection with smoking, but in fact smoking also damages the heart and blood vessels. Patients with kidney failure are already at increased risk of heart and blood vessel problems, so having kidney failure and being a smoker greatly increases your risk of developing these serious problems.

If you want to stop smoking, then we will try to help you with this.

Alcohol

You can still drink alcohol if you have kidney failure. The important thing to remember is to keep the total volume within your daily fluid restriction. Of course, just like people with normal kidney function, you should avoid drinking excessive amounts of alcohol. The maximum recommended alcohol intake is 2–3 units per day for a woman, and 3–4 units per day for a man. The renal dietitians can give you more guidance on how much alcohol makes up 1 unit.

Life expectancy

This is a difficult area to talk and think about. Kidney failure can have ‘knock-on’ effects on other parts of your body. In particular, heart disease and blood vessel problems are more common in people with kidney failure. These problems may reduce life expectancy in people on dialysis or following transplantation. If you want to talk more about this or would like to consider making plans for your future care, then please speak to your consultant.

6 Coping with kidney failure

Having kidney failure brings with it a number of changes to your way of life that will affect you for the rest of your life. This can sometimes make adjusting to kidney failure seem like a huge task. However, as we have shown, the changes that are necessary should not stop you from continuing to enjoy the sort of activities that you have always enjoyed.

People react to kidney failure in a number of ways. Some see it as a challenge. Others become worried about what will happen to them. Other people try not to think about kidney failure at all. These are all normal reactions to the changes that kidney failure brings.

Most people cope with their condition in different ways at different times.

Learning about kidney failure and what it involves can help you to cope. You can do this by reading about it or by talking with members of the Renal Team. Feeling supported by other people is also very helpful.

Having someone in the family with kidney failure affects all family members. It can take time for family and friends to realise and understand what is happening. You may avoid telling people about your kidney disease at first. People may not know what to say to you when they know you have kidney disease and this can feel awkward.

Talking to family or friends about your kidney failure and how it affects you can help them understand more fully what it is like, which means they are able to support you better.

Finding ways of coping involves thinking about your situation. Most situations that people find themselves in have both positive and negative aspects to them.

Attempting to find positive things about kidney failure can be helpful.

Changing your thoughts from focusing on your kidney failure to thinking about a hobby, learning how to relax or setting new challenges can all be good ways of increasing positive thoughts.

To help your family understand what having kidney failure means for you and for them, we have put together two guides. One is called *Grown-ups with Kidney Failure: A guide for children*. The other is *Living with Kidney failure: a guide for relatives and carers*. You can get copies of either of these guides from any member of the Renal Team.

The Renal Team are here to support you and your family, so please do not hesitate to contact us with any concerns or questions any of you may have.

7 Support from the Renal Team

There are many things that the Renal Team can do to help you, but we can only help if you talk with us about any issues that concern you. Your concerns will always be treated with respect. Discussion with the doctors and nurses may lead to you being offered assistance from other members of the Renal Team, such as the clinical psychologist, the dietitian, physiotherapist or the social worker, or from someone outside the Renal Team, such as an occupational therapist.

If you feel it might be helpful to meet with any of these people, please speak with one of the doctors or nurses involved with your care. They will be able to refer you to the correct person.

The renal psychologist

The renal psychologist can help if you find it becomes difficult to cope with living with kidney failure. An appointment with the renal psychologist usually last 50 minutes and takes place in the hospital. You may meet only once, or every few weeks or have regular weekly or fortnightly appointments. As part of the Renal Team the psychologist works with pre-dialysis, dialysis and transplant patients and can assist in many different ways including:

- helping you to understand your emotional reactions
- looking at the ways you cope with kidney failure and developing other coping strategies
- helping families to cope with the changes that happen when someone in their family has kidney failure
- allowing you to share your thoughts and feelings about the treatment choices you are making with your doctors.

The renal social worker

The renal social workers works within the Renal Team with patients and their families and carers to enable them to make the best possible use of the services available.

The renal social workers can give you advice and support on a range of personal, emotional and practical matters, including:

- benefits entitlement and finances
- grants from charities
- referral to occupational therapists for aids and adaptations
- liaison with housing departments
- hospital discharge planning
- home care, warden call and telecare
- home care, meals-on-wheels, warden call systems, telephone installation
- residential or nursing home care
- holidays and holiday grants.
- employment issues
- help for carers
- family support

Many patients ask the renal social worker about benefits. Having kidney failure does not automatically entitle you to specific benefits, but the social worker can

help you access those which you may be entitled to. The National Kidney Federation has a very good pack on benefits which you can get from their helpline on 0845 6010209. or you can download it from their website, www.kidney.org.uk/help/uk-state-benefits/benefits-knowyourbenefits. There is also a lot of helpful information on their website, www.kidney.org.uk.

Your GP

Although your kidney failure will be looked after by the consultant nephrologist (kidney specialist) at the hospital, you will continue to have contact with your own GP.

Occupational therapists

Occupational therapists are available to help you cope with the everyday tasks that may become more difficult when you are living with kidney failure. They will work alongside you to help you gain more confidence and independence with practical tasks, and they can also provide appropriate equipment or adaptations that you may need.

Physiotherapists

Physiotherapists can work with you to help with any mobility problems you have. They may be able to offer a tailored programme to maximise your ability to exercise.

You can access the occupational therapist and physiotherapist via the medical or nursing staff or with the renal social worker.

8 Other sources of information and help

You can get more information and help from a number of sources, including:

- your renal unit
- national and local patient organisations
- the internet.

Your renal unit

Your renal unit will have a number of information leaflets and books for you to look at and borrow.

National patient organisations

There are three national organisations for people with kidney failure. These are:

- the National Kidney Federation (NKF)
- Kidney Research UK (KRUK)
- the British Kidney Patient Association (BKPA)

The Kidney Patient Association (KPA) has a local group which meets regularly and is affiliated to the National Kidney Federation. It is always looking for people to take part and help with social events and fundraising. If you'd like to know more, the dialysis units and the renal specialist nurses have copies of the York Kidney Patient Association leaflet and application form.

There are two other national patient organisations you might find useful:

- Diabetes UK
- the Transplant Support Network (TSN)

The National Kidney Federation (NKF)

Formed in 1979 to represent the interests of all kidney patients throughout the United Kingdom, the National Kidney Federation produces helpful leaflets and a quarterly magazine, and also operates the National Kidney Helpline.

The National Kidney Federation (NKF)

The Point,
Coach Road,
Shireoaks,
Worksop,
Notts
S81 8BW,

Telephone: 01909 544999

National Kidney Helpline: 0845 601 0209

www.kidney.org.uk

Kidney Research UK (KRUK) (Formerly The National Kidney Research Fund)

Established in 1967 to provide a national fund for kidney research, Kidney Research UK aims to improve the understanding of renal failure, its causes, treatment and management, with over £10 million invested in research at any one time. The Fund also supports kidney patients directly with information to help them cope with their condition.

Kidney Research UK

Nene Hall
Lynch Wood Park
Peterborough
PE2 6FZ

Telephone: 0845 070 7601

www.kidneyresearchuk.org

The British Kidney Patient Association (BKPA)

Set up by Mrs Elizabeth Ward OBE in 1975 after her son was diagnosed with kidney failure, the British Kidney Patient Association offers support, advice and financial help, and also financial support to kidney units throughout the UK to help improve kidney services and patient care

The British Kidney Patient Association (BKPA)

Rosemary Macri
3 The Windmills
St Mary's Close
Turk Street
Alton
Hants
GU34 1EF

Telephone: 01420 541424

www.britishkidney-pa.co.uk

Diabetes UK

If your kidney failure was caused by diabetes, you may be interested in Diabetes UK, which was the first medical self help charity to be set up in this country. It helps people with diabetes and supports diabetes research. Diabetes UK runs a Careline offering information and support.

Diabetes UK

Macleod House

10 Parkway

London

NW1 7AA

Telephone: 020 7424 1000

Careline: 0845 120 2960 Email: careline@diabetes.org.uk

www.diabetes.org.uk

The Transplant Support Network (TSN)

The Transplant Support Network provides support for patients, carers and families involved in the transplantation of organs.

The Transplant Support Network

6 Kings Meadow Drive

Wetherby

West Yorkshire

LS22 7FS

Support Lines: 0800 027 4490/1

E-mail: admin@transplantsupportnetwork.org.uk

www.transplantsupportnetwork.org.uk

The internet

Useful websites include:

- www.aakp.org (the American Association of Kidney Patients)
- www.nephron.com (lots of information on kidney disease)
- www.basw-renal.co.uk (renal social work website)
- www.kidneypatientguide.org.uk
- www.renalpatientview.org
- www.gov.uk/government/organisations/department-of-health
- www.eurodial.org (information about dialysing in Europe)
- www.globaldialysis.com (holiday and travel information)
- www.organdonation.nhs.uk
- <http://www.shreddialysis-care.org.uk/>

9 Drugs prescribed for dialysis patients

In this section we will look at the drugs that are most commonly prescribed for people who are on dialysis.

Drugs for anaemia

EPOETINS (erythropoietin): E.g. **Aranesp, NeoRecormon, Eprex**: EPO is a hormone that stimulates the bone marrow to produce red blood cells. It is produced naturally by healthy kidneys, but has to be administered by injection if your kidneys fail. The injection, known as an erythropoiesis stimulating agent (ESA) will be prescribed to try to reduce anaemia. Your doctors and nurses will show you how to inject yourself, or make arrangements for a nurse at your GP

practice to give the injection to you. You will need to have regular blood pressure and blood checks.

Side-effects: some patients experience a bit of discomfort at the injection site.

Iron supplements e.g. ferrous fumarate: These are prescribed to try to reduce anaemia. They are often taken three times a day. If you are also taking calcium tablets or some antibiotics (check with the pharmacist), you should try to take the iron tablets at least one hour before or after these tablets.

Side-effects: can include constipation, diarrhoea or feeling sick. If you feel sick, try taking the tablets with food. You may notice your stools or urine becoming a darker colour. This is normal, and nothing to worry about.

Drugs to control blood pressure

There are different groups of drugs for treating blood pressure problems. These groups are: beta-blockers, calcium antagonists, ACE inhibitors, angiotensin II blockers and alpha-blockers. You may be taking one or more medicines to control your blood pressure. This is because medicines in the different groups act in different ways and a combination of the different tablets might be needed to lower your blood pressure.

Beta-blockers

Atenolol, bisoprolol: usually taken once a day, in the morning.

Side-effects: can include tiredness.

Calcium antagonists

Amlodipine: usually taken once a day, in the morning.

Side-effects: can include headache, dizziness and ankle swelling.

Nifedipine: usually taken once or twice a day. You should avoid eating grapefruit or drinking grapefruit juice if you are taking nifedipine.

Side-effects: can include headache, flushing and ankle swelling.

ACE inhibitors

Lisinopril, perindopril, ramipril: these drugs reduce your blood pressure, and may help your breathing if you have a heart problem. If you are prescribed one of these drugs, you will probably take it once a day, in the morning, but sometimes we prescribe it twice a day.

Side-effects: can include tiredness and feeling sick. If you feel sick, try taking it with food. Sometimes you may develop a persistent dry cough. If this occurs, tell your doctor, who may be able to consider an alternative for you.

Angiotensin II blockers

Losartan, candesartan: these drugs reduce your blood pressure, and may help your breathing if you have a heart problem. They are very similar to the ACE inhibitors, but are less likely to cause a persistent dry cough. They are a useful alternative for patients who have to discontinue an ACE inhibitor because of persistent cough. If you are prescribed one of these drugs, you will probably take it once a day, in the morning.

Side-effects: side-effects are usually mild, but low blood pressure leading to dizziness may occur.

Alpha-blockers

Doxazosin: usually taken once a day, at bedtime, but sometimes we prescribe it twice a day.

Side-effects: can include dizziness, headache and feeling sick. If you feel sick, try taking it with food.

Diuretics

Diuretics (also known as water tablets) are medicines that increase your urine volume and frequency. They are usually prescribed when your kidneys are still working, to help them remove excess water from your body.

Bumetanide and furosemide: usually taken in the morning, and possibly at lunchtime as well. It is best not to take either of them at bedtime, or else you may need to go to the toilet in the middle of the night.

Side-effects: can include dizziness or feeling sick. If you feel sick, try taking the tablets with food.

Drugs to reduce cholesterol

Atorvastatin, fluvastatin, pravastatin, rosuvastatin, simvastatin: these drugs are given to reduce your blood cholesterol level. They should be taken at bedtime.

Side-effects: can include headache, feeling sick and muscle pain. If you feel sick, try taking the tablets with food. If you suffer from muscle pain, tell your doctor as soon as possible.

Phosphate binders

Phosphate binders reduce the amount of phosphate that is absorbed from food into your body. There are several different phosphate binders available and we may change your medicine or the number of tablets you are taking according to your blood calcium and phosphate results. It is important that you take the tablets regularly just before or with meals. The dietitian may give you further advice about your diet and when to take your phosphate binders.

Calcium carbonate phosphate binders

Calcichew, Calcichew Forte, Calcium 500: these tablets need to be taken about five minutes before your meals, or with your meals. They can be chewed or dissolved in the mouth before swallowing. Calcium 500 tablets can be swallowed whole without chewing.

Side-effects: can include constipation.

Other phosphate binders

Calcium acetate (Phosex tablets or Phoslo Capsules): the calcium acetate tablets have a bitter taste if chewed, so they should be swallowed whole with your meals. If you find the taste unpalatable ask your doctor to consider changing to the capsules.

Side-effects: can include constipation or diarrhoea.

Sevelamer: a phosphate binder that may be prescribed if you have high calcium levels and high phosphate levels. These tablets need to be taken just before your meals, or with your meals. The tablets are big and you may find that you have problems swallowing them. If this happens you should let the pharmacist know. There are two forms of sevelamer. The renal team currently prescribes sevelamer hydrochloride (Renagel).

Side-effects: can include diarrhoea or constipation.

Aluminium hydroxide (Alucaps): a phosphate binder that may be prescribed if you have high calcium levels and high phosphate levels. These capsules need to be taken with your meals. The capsules are big and you may find that you have problems swallowing them. If this happens you should let the pharmacist know.

Side-effects: can include constipation. Also, aluminium can build up in your body, which can cause problems. We check the aluminium level in your blood regularly to avoid these problems happening.

Lanthanum: another phosphate binder which may be prescribed as an alternative to sevelamer or aluminium hydroxide if you have high calcium and high phosphate levels. These tablets are chewed and should be taken with or immediately after meals.

Side-effects: can include nausea, diarrhoea and headache and constipation. Let your doctor or renal pharmacist know if you develop side effects.

Vitamin D

Alfacalcidol: a vitamin D capsule, given because kidney failure can cause vitamin D deficiency. It is prescribed to control the development of renal bone disease. It is usually taken in the morning, either every day or just two or three times a week. Sometimes your doctor will advise you to take the capsules at night to reduce the amount of calcium and phosphate you absorb from your food. Always follow the doctor's instructions about how to take these capsules.

Drugs for itching

Chlorphenamine and hydroxyzine: these belong to a group of medicines called antihistamines. They are used to reduce itching that can happen as chemicals build up in your body.

Chlorphenamine (also known as Piriton) and other antihistamines can be bought from your local pharmacy. Take care not to take twice the recommended dose, i.e. do not take antihistamines you have bought yourself as well as those prescribed by your doctor.

Side-effects: can include drowsiness. If you feel drowsy, do not drive or operate machinery.

Cetirizine and loratadine: these are non-sedating antihistamines which may be prescribed for itching. They cause less drowsiness than antihistamines like chlorphenamine.

Drugs to thin the blood

Aspirin: given to help thin your blood. It is normally taken once a day, in the morning. The soluble tablets can be dissolved in a small amount of water before swallowing. Always take with food.

Side-effects: can include stomach irritation or indigestion.

Clopidogrel: similar to aspirin, this helps to thin your blood. It is usually given in combination with aspirin for patients who have severe heart disease and angina. It may be used without aspirin for patients who are allergic to or get severe stomach upset with aspirin.

Side-effects: can include stomach irritation or indigestion.

Ticagrelor: similar to aspirin, this helps to thin your blood. It is usually given in combination with aspirin for patients who have severe heart disease and angina. It may be used without aspirin for patients who are allergic to or get severe stomach upset with aspirin.

Side-effects: can include stomach irritation or indigestion.

Drugs to prevent your blood clotting

Warfarin: belongs to a group of drugs called anticoagulants. Warfarin decreases the ability of the blood to clot. You will usually be prescribed it to reduce the risk of blood clots forming in the heart, lungs or blood vessels.

The pharmacist will talk with you about warfarin and give you a yellow warfarin booklet which includes more information about it. Because warfarin decreases the ability of the blood to clot, we need to check your progress and take blood tests at regular intervals whilst you are taking this medicine. The doctor or pharmacist will

tell you what dose to take. The warfarin dose and blood results will be recorded in your warfarin booklet, which you should carry with you when you come for dialysis or for a clinic appointment to see the consultant.

Always tell your doctor, pharmacist or nurse if you are taking any new tablets, including any that you buy without a prescription.

Side-effects: these are listed in the yellow warfarin booklet that you will be given. In particular you may experience prolonged bleeding from small cuts, or bleeding gums when you clean your teeth. If the bleeding cannot be stopped, you must let your GP or the renal unit know as soon as possible.

Drugs to reduce stomach acid

Ranitidine: reduces the amount of acid in your stomach. Usually taken once or twice a day.

Side-effects: can include tiredness, headache and dizziness.

Omeprazole and lansoprazole: these drugs also reduce the amount of acid in your stomach. They are usually taken first thing in the morning, before breakfast.

Side-effects: can include diarrhoea or constipation, and stomach upsets.

Drugs for constipation

Lactulose: a liquid that is given to relieve constipation. It is usually taken twice a day, and may take a day or so to be effective.

Side-effects: can include belching and stomach cramps.

Senna: also relieves constipation. This is usually taken once or twice a day.

Side-effects: can include stomach cramps.

Docusate sodium: another drug prescribed for constipation. The tablets are usually taken once or twice a day, in the morning and at bedtime.

Side-effects: can include stomach cramps.

Movicol or Laxido: a sachet containing powder which has to be mixed with 125mL water before taking. The water is not absorbed so this can be used even if you are on a fluid restricted diet. It is usually taken twice a day to start but may need to be taken less often. The sachets contain potassium and regular use of these sachets may not be suitable for you if your potassium levels are high.

Side-effects: Abdominal discomfort, diarrhoea, vomiting, nausea, abdominal distension,

Drugs for diarrhoea

Loperamide: used to reduce or stop diarrhoea. It is important that you do not take more than the dose prescribed by your doctor. If you buy these from your local pharmacy, always check on the packet what the maximum dose is. If you have had a transplant or you are taking medicines that affect your immune system (for example prednisolone or cyclophosphamide), you should tell your GP, consultant or the transplant specialist immediately if you have severe or persistent diarrhoea.

Side-effects: can include stomach cramps and abdominal bloating.

Pain relief

Paracetamol: Simple painkillers like paracetamol are safe to take if you have kidney failure. The usual dose is one or two tablets every four to six hours, but no more than eight tablets in 24 hours. Do not take other medicines containing paracetamol at the same time as paracetamol. Try taking regular doses of paracetamol to control the pain before taking stronger painkillers.

Side-effects: can include feeling sick.

Codeine, dihydrocodeine, tramadol: these are opioid-based painkillers which are usually used in addition to paracetamol when paracetamol alone does not control the pain. Combination preparations are usually called co-codamol or co-dyamol. Be careful not to take more than the recommended dose in 24 hours. Some patients with kidney failure may be more sensitive to these medicines so you should take care to watch for side-effects and discuss any problems with your doctor, pharmacist or nurse.

Side-effects: include constipation (which may be severe if you take these tablets regularly), drowsiness or feeling confused.

Stronger painkillers

Morphine, buprenorphine, fentanyl, oxycodone: these painkillers may be prescribed if you have very severe pain that is not controlled by paracetamol, codeine or tramadol. In people with kidney failure, the side-effects of these stronger painkillers may be more noticeable, so it is important that you follow the instructions carefully. Never take more than the prescribed dose without checking with a doctor. Let your doctor, pharmacist or nurse know if you think you have got any of the side-effects listed on the information sheet.

Side-effects: include constipation, drowsiness and confusion, feeling weak or faint, dizziness, bad dreams and difficulty breathing.

Nonsteroidal Anti-Inflammatory Drugs (NSAIDS)

Ibuprofen and diclofenac: these Nonsteroidal Anti-inflammatory drugs (NSAIDS) reduce pain and inflammation and are sometimes used if you have arthritic pain. Your renal consultant may tell you to avoid these painkillers because they can make your kidney failure worse or can cause an ulcer in your stomach. Never buy painkillers without checking with the pharmacist or your doctor that they will be safe for you to take. Always take these tablets with food.

Side-effects: can include stomach irritation or indigestion.

Other drugs prescribed for patients with renal failure

Sodium bicarbonate: a tablet that you may need to take to balance acid or potassium build-up. It is often taken two or three times a day.

Side-effects: can include feeling sick. If you feel sick, try taking the tablets with food.

10 Vaccinations

Certain vaccinations are recommended for patients with kidney disease, and for people who are likely to have dialysis treatment or a kidney transplant. We have included a form for you to record the dates of your vaccinations if you wish to. Your kidney specialist will explain which vaccinations you need and when.

Hepatitis B

The Department of Health recommends that all patients with chronic kidney failure should be vaccinated against hepatitis B as soon as it is clear that they might need dialysis or a transplant.

Your consultant will usually write to your GP to arrange a course of hepatitis B vaccinations for you. Let your hospital doctor or nurses know as soon as you have completed the course of injections.

Influenza

If you have chronic kidney failure, are on dialysis or have had a kidney transplant or drugs that suppress your immune system, it is recommended that you have a flu vaccine every winter. Your GP will usually write to you about this, but if you haven't received a letter by the middle of October, check with your surgery.

Pneumonia

The Department of Health now recommends that all patients with chronic kidney failure should be vaccinated against pneumonia. This vaccination is required every five years.

Other information about vaccines and holiday medicines

Most vaccines are safe for patients who have chronic kidney disease. However, if you have had a transplant or you are taking medicines that depress your immune system, there is a group of vaccines called 'live vaccines' that must be avoided. Your GP or pharmacist will be able to advise you about these.

You may require vaccinations or malaria prophylaxis if you are planning to travel abroad. Always check any travel advice you have been given with your GP or consultant before having any vaccinations or taking any medication. The choice and dose of malaria tablets may need to be changed depending on how well your kidneys are working.

Glossary of terms

access a way of gaining entry to the bloodstream to perform haemodialysis.

Advance Care Plan (ACP) patients record their wishes for their end of life care.

anaemia a condition in which there is a lack of red blood cells. Anaemia can lead to shortness of breath.

ankle oedema swelling in the ankles caused by a build-up of fluid.

APD (automated peritoneal dialysis) a type of peritoneal dialysis in which the fluid is exchanged by a machine.

arteriovenous fistula (also fistula) the point at which a vein and an artery are joined under the skin to increase the blood flow in the vein, which can then be 'needled' to perform haemodialysis. The fistula is usually made under local anaesthetic at the wrist or elbow by a surgeon.

Assisted Automated peritoneal dialysis (AAPD) – automated peritoneal dialysis supported by a daily visit by a trained carer to set up an automated peritoneal dialysis machine.

automated peritoneal dialysis (APD) a type of peritoneal dialysis in which the fluid is exchanged by a machine.

cadaveric transplant a kidney transplant received from someone who has died (a cadaver donor).

CAPD (continuous ambulatory peritoneal dialysis) a type of peritoneal dialysis in which the fluid is exchanged manually 4 times per day.

catheter a flexible hollow tube used to gain access to the body, for example to a vein, the peritoneal cavity or the bladder.

cholesterol a type of fat found in the body that can be measured in the blood.

creatinine a waste product created during muscle usage. When creatinine is measured in the blood it gives a good indication of how the kidneys are working.

dialyser the part of the haemodialysis machine that filters the blood, removing the body's waste products and excess fluid.

dialysis an artificial process to remove the body's waste products and excess water. There are two different sorts of dialysis: haemodialysis (HD), and peritoneal dialysis (PD).

dialysis fluid the fluid into which the molecules of waste products and water move during the process of dialysis.

diuretics drugs that help the kidneys remove water from the body.

dry weight (also ideal or target weight) a person's weight with the correct amount of fluid in the body, i.e. when the person is not fluid overloaded or dehydrated.

electrolytes mineral salts found in the blood whose levels are controlled by the kidneys. When measured in the blood, they give a good indication of the functioning of the kidneys.

EPO (erythropoietin) a hormone that stimulates the bone marrow to produce red blood cells. It is produced by healthy kidneys, but can be administered as an injection if the kidneys fail.

erythropoietin (EPO) a hormone that stimulates the bone marrow to produce red blood cells. It is produced by healthy kidneys, but can be administered as an injection if the kidneys fail.

exit site the point at which a dialysis catheter comes out through the skin.

fistula (also arteriovenous fistula) the point at which a vein and an artery are joined under the skin to increase the blood flow in the vein, which can then be 'needled' to perform haemodialysis. The fistula is usually made under local anaesthetic at the wrist or elbow by a surgeon.

fluid overload a condition in which there is too much fluid in the body. This usually leads to high blood pressure and weight gain above the person's dry weight. The extra fluid tends to gather around the ankles (ankle oedema) and in the lungs (pulmonary oedema).

glucose a type of sugar. It is the main constituent of peritoneal dialysis fluid, and it enables water to move from the person's body into the dialysis fluid.

haemodialysis (HD) the process of filtering the blood outside the body using a dialysis machine. Each haemodialysis session lasts approximately four hours, and usually takes place three times a week.

haemoglobin the substance in red blood cells that carries oxygen around **the body**. A low haemoglobin level indicates anaemia.

HD (haemodialysis) the process of filtering the blood outside the body using a dialysis machine. Each haemodialysis session lasts approximately four hours, and usually takes place three times a week.

hypertension high blood pressure.

hypotension low blood pressure.

ideal weight (also dry or target weight) a person's weight with the correct amount of fluid in the body, i.e. when the person is not fluid overloaded or dehydrated.

intravenous infusion fluid given directly into a vein.

membrane a very thin layer of material. In peritoneal dialysis it is the peritoneum inside the body that is the membrane used to filter out waste products and excess water.

nephritis a type of inflammation of the kidneys.

nephrologist a doctor who specialises in kidney disease.

oedema a build-up of fluid in the body causing fluid overload. Most common are ankle or pulmonary oedema.

parathyroid hormone (PTH) a hormone produced by four glands in the neck. It normally helps control calcium levels. In people who have kidney failure, too much may be produced, leading to high calcium levels. This can cause bone calcification and pain.

PD (peritoneal dialysis) a method of dialysis which uses the body's peritoneum as the filter to remove the body's waste products and excess water. There are two different types of peritoneal dialysis: automated peritoneal dialysis (APD), and continuous ambulatory peritoneal dialysis (CAPD).

peritoneal cavity the space between two layers of the peritoneum.

peritoneal dialysis (PD) a method of dialysis which uses the body's peritoneum as the filter to remove the body's waste products and excess water. There are three different types of peritoneal dialysis: automated peritoneal dialysis (APD), continuous cyclic peritoneal dialysis (CCPD) and continuous ambulatory peritoneal dialysis (CAPD).

peritoneum a natural membrane covering the body's abdominal organs, which is used in peritoneal dialysis to filter out the body's waste products and excess water.

phosphates mineral salts that work with calcium to keep bones strong. The kidneys are involved in controlling the amounts of phosphates in the blood. When the kidneys fail, blood phosphate levels tend to become too high, which can cause low blood calcium levels, leading to a condition known as renal bone disease.

platelets small cells in the blood that helps it to clot.

potassium a mineral found in the blood which needs to be monitored in people with kidney failure as too much or too little can be dangerous. It may need to be restricted in the diet.

proteins components of the body which are essential to its structure, functioning and repair.

PTH (parathyroid hormone) a hormone produced by four glands in the neck. It normally helps control calcium levels. In people who have kidney failure, too much may be produced, leading to high calcium levels. This can cause bone calcification and pain.

pulmonary oedema too much fluid gathered in the lungs as a result of fluid overload.

rejection the process by which the body's immune system recognises that a transplanted kidney is not 'its own', and then tries to damage it.

renal relating to kidneys.

renal bone disease a condition leading to weak bones, caused by high phosphate levels and by low calcium and vitamin D levels.

Shared care unit -

target weight (also dry or ideal weight) a person's weight with the correct amount of fluid in the body, i.e. when the person is not fluid overloaded or dehydrated.

tissue type a person's tissue type is determined by a set of inherited characteristics found on the surface of cells. These characteristics are so diverse that it is unusual for there to be an exact tissue match between a donor and recipient, but the more characteristics that match, the more likely it is that a transplant will succeed.

transplant can mean either a transplant operation or a transplanted kidney.

urea and electrolytes mineral salts and chemicals found in the blood, whose levels are controlled by the kidneys. When measured in the blood, they give a good indication of the functioning of the kidneys and of how well dialysis is working.

ureters the body's tubes that take urine from the kidneys to the bladder.

urethra the body's tube that takes urine from the bladder to outside the body.

vascular access gaining entry to the bloodstream via a blood vessel to perform haemodialysis.

wet foods foods which are made mainly from fluids, and so need to be counted as part of a fluid allowance.