

Your kidneys, your choice

A guide to living
with kidney failure

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Have you been diagnosed with kidney failure
(chronic kidney disease stage 5)?

Are you thinking about your treatment options?

Are you wondering what information
and support is available?

If the answer to any of these questions is **yes**,
then this booklet is for you.

The kidneys

This booklet tells you more about:

- living with kidney failure
- how your kidneys work and what they normally do
- how kidney disease may make you feel
- your treatment options – transplant, dialysis and supportive care
- what you can do to keep yourself as healthy as possible
- the support that is available.

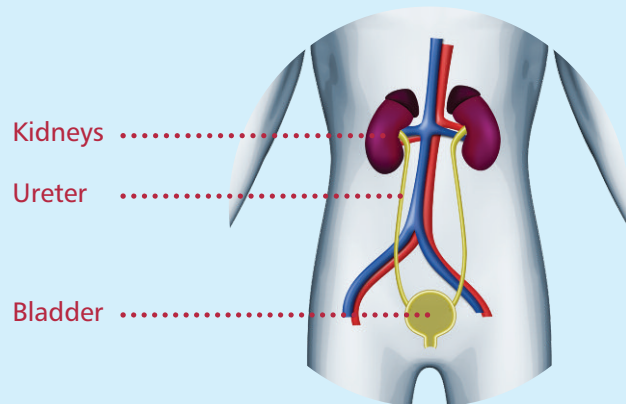
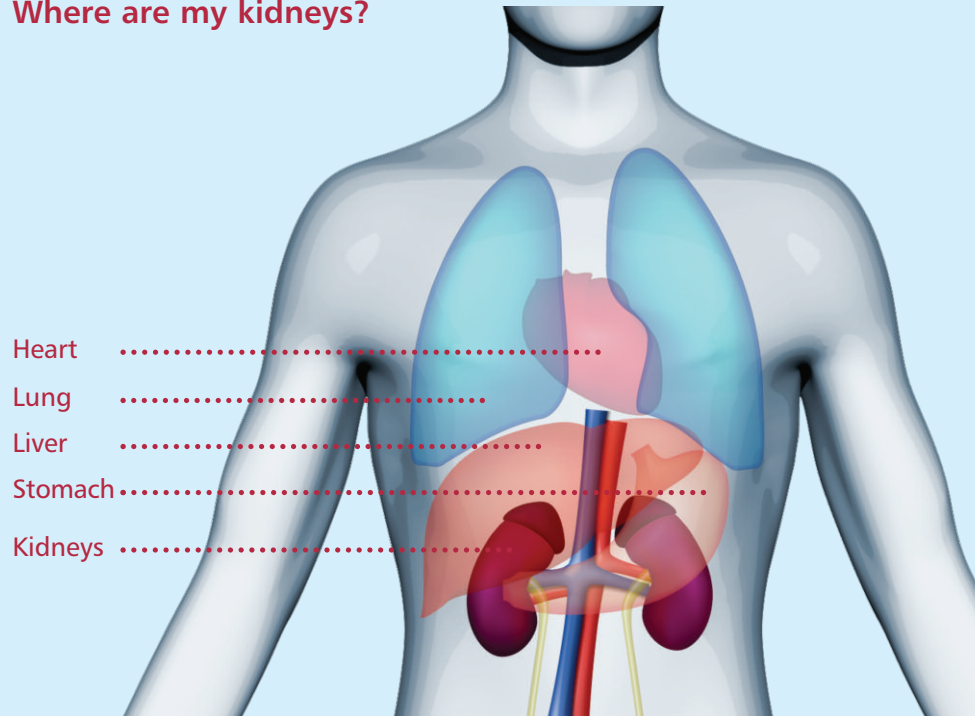
You may decide to read this booklet all at once or prefer to read just a chapter or two at a time. You might find it helpful to share the information in this booklet with your family and friends. There is also a film available, *Your kidneys, your choice*, this tells you more about living with kidney failure and features patients telling their stories. This is available online at www.mykidney.org.uk. Please ask a member of the kidney team for details.

At the end of each chapter we suggest some questions that you might want to ask when you come to the clinic. You might find it helpful to write down two or three questions to ask each time you attend. Whatever your questions, big or small, we are always happy to answer them.

Most people have two kidneys. Your kidneys are two bean-shaped organs at the back of your body, below your ribs.

The diagram overleaf shows where your kidneys are in relation to your other major organs.

Where are my kidneys?



From the kidneys urine passes through your ureters to your bladder.

What do my kidneys do?

The functions of the kidney include:

- filtering blood to make urine, enabling your body to get rid of waste and water it does not need, and also regulating the salts and minerals in your blood
- controlling your blood pressure
- producing the hormone erythropoietin (EPO) so your body can make red blood cells and stop you becoming anaemic
- keeping your bones healthy by helping to balance your levels of calcium and phosphate.

What is kidney failure?

Kidney failure means that your kidneys are not working properly and that the condition is likely to last for the rest of your life. Your kidneys are unlikely to start working again.

There is no cure for kidney failure but dialysis and transplantation are very effective treatments that take over the work that your kidneys normally do. Some people choose not to have dialysis or a transplant. This is called supportive care. You can read more information about these treatments in the next three chapters.

How did you find out that I have kidney failure?

The problem with your kidneys may have been discovered through one of the following ways:

- a routine urine test
- a very high blood pressure reading
- a routine blood test.

Your GP may have been monitoring you for kidney disease because you have another condition such as diabetes or high blood pressure, or you have family history of kidney disease.

If your doctor finds something is wrong with your kidneys, they may do more tests. This may include more blood tests, x-rays, ultrasound scans and possibly a kidney biopsy (where a tiny piece of tissue is removed from your kidney and examined under a microscope). These tests are needed to see the exact damage to your kidneys and to determine if any specific treatment is necessary.

What are the symptoms of kidney failure?

In the early stages you often have no symptoms. Later on, you may have some or all of these symptoms at different times:

- tiredness
- lack of appetite
- sickness
- cramp in your legs
- itching
- swollen ankles
- shortness of breath
- changes to sleep patterns
- less interest in sex
- feeling cold.

Many of these symptoms will improve when you start treatment.

Can kidney failure happen with no symptoms?

Yes, often people do not feel unwell and may not have any significant symptoms. You might only find out from a routine blood test that your kidneys are not working properly and that you need to start some treatment.

What causes kidney failure?

There are a lot of conditions that can damage your kidneys and sometimes it is a result of the normal ageing process as kidneys scar gradually with age and are unable to repair themselves.

Here are some of the other common causes:

- **Diabetes Mellitus** – a condition in which there is too much sugar in the blood. It can be treated by insulin, tablets or diet. It is the single most common cause of kidney failure and usually occurs in people who have had diabetes for longer than ten years.
- **High blood pressure** – also called hypertension.
- **Glomerulonephritis** – a general term meaning the kidneys become inflamed and damaged.
- **Pyelonephritis** – an inflammation of the kidneys' drainage system, usually caused by an infection.
- **Renovascular disease** – a narrowing of the arteries that supply blood to the kidneys. It is often associated with smoking and too much cholesterol in the body.
- **Obstructive nephropathy** – a blockage in the flow of urine which causes damage to the kidneys. In men it is often caused by the prostate gland becoming enlarged, particularly if they are over 60 years of age. In rare cases, it happens to women and is connected to gynaecological problems.
- **Polycystic kidney disease (PKD)** – a condition which runs in families. If you have PKD you will have lumps, known as cysts, on your kidneys.

The National Kidney Federation has leaflets about the different causes of kidney disease. There is also information on their website. Contact details are on page 97.

Sometimes it is not possible to find out why your kidneys have failed but this does not usually affect your treatment.

How do you know the extent of my kidney damage?

When we do your regular blood tests at clinic, we can use the results to calculate your estimated Glomerular Filtration Rate (eGFR). This gives us a rough idea of the amount of remaining healthy kidney function provided by your kidneys.

Young people with completely healthy kidney function will have an eGFR of 90% or more but people can remain well with much less than this.

You might start to experience some significant symptoms once your percentage of remaining kidney function is down to 20-30% of normal. Once your kidney function reaches 8-12% of normal, you will need to have a specific treatment in the form of dialysis, transplantation or supportive care.

Stages 1 and 2 (mild or early stage chronic kidney disease (CKD)):

Your kidney function is 60% or more but your urine test, kidney x-ray or kidney biopsy show some signs of kidney damage.

Stage 3 (moderate CKD):

Your percentage of remaining kidney function is 30 - 59%.

Stage 4 (advanced CKD):

Your percentage of remaining kidney function is 15 - 30%. This is the point at which you might start to feel symptoms and this is also the time to start thinking about treatment options for kidney failure.

Stage 5 (kidney failure):

Your percentage of remaining kidney function is less than 15% and you may need to start treatment in the form of dialysis, transplantation or supportive care.

Most people reading this booklet will be at stage 4 or 5.

Can I slow down the damage to my kidneys?

The most important thing you can do is to attend clinic appointments, no matter how you feel, and to keep taking any prescribed medications. You can also help by:

- keeping your blood pressure down
- eating healthily
- taking regular exercise
- giving up smoking
- reducing your alcohol intake
- if you are diabetic, getting your diabetes under control
- avoiding a type of painkiller called a non-steroidal anti-inflammatory drug (also known as NSAID), such as ibuprofen (Nurofen®) as these can cause further kidney damage.

We may also prescribe you some medications to help protect your kidneys and give you advice on avoiding medications that may further damage your kidneys.

For a small percentage of patients who have more unusual causes of their kidney problem, there may be some additional, more specific treatments to help their kidneys, such as medications to suppress their immune system.

What will happen to me in the future?

Many people with kidney failure enjoy a good quality of life. However, no one can accurately predict the future. Your outlook will be affected by your age and whether you have other medical conditions, such as heart disease or diabetes. Statistics can give you a general indication about survival for kidney patients, but these only give an average and do not reflect the outcome for each individual.

What are my treatment options?

We will talk to you about the amount of kidney function you have each time you come to the clinic. When you have about 20% of kidney function left, your kidney team will start to talk about which treatment is right for you.

Your treatment options are:

- **dialysis** – an artificial process by which the toxic waste products of food and excess water are removed from your body
- **kidney transplant** – a kidney removed from one person (the donor) and given to another person (the recipient)
- **supportive care** – (sometimes called conservative care) choosing not to have dialysis or a kidney transplant and managing the symptoms of kidney failure with support from the healthcare team. This option is for those with a limited life expectancy due to other serious health conditions.

This booklet will tell you more about these treatments. You are likely to have more than one treatment in your lifetime.

More information

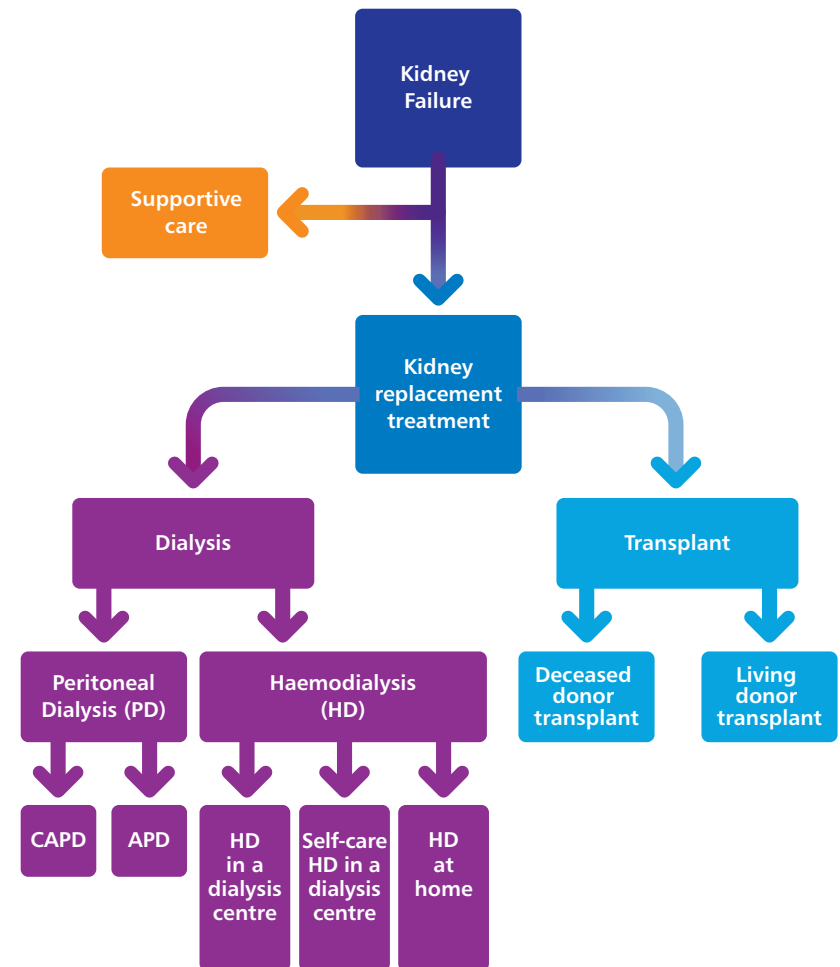
What can I do?

- Come to your clinic appointments regularly, even if you feel well, because it is important that you have your blood checked regularly so we can monitor your condition.
- Take all prescribed medications.
- Eat healthily, take regular exercise, give up smoking and reduce your alcohol intake.
- If you are diabetic, get your diabetes under control.
- Start thinking about which treatment you would prefer.

Questions you might like to ask

- What is the cause of my kidney disease?
- What stage of kidney disease am I at?
- What percentage of my kidneys are working?

Kidney treatment decision tree



Having Dialysis

Dialysis does the job your kidneys normally do, cleaning your blood by removing waste and fluid your body does not need. Dialysis can be carried out at home or at a dialysis centre.

There are two types of dialysis: Haemodialysis (HD) and peritoneal dialysis (PD)

Which is the best dialysis for me?

For most people each type of dialysis will work equally well but some people will have a medical reason which means one option may be better than another. Please discuss this with your doctor or nurse.

Some of the other factors that will affect your choice will include family and work commitments, leisure or travel. You can compare the differences between the dialysis treatments using the table on pages 28-37.

You may also wish to talk to other kidney patients who have personal experience of dialysis, this is known as Peer Support, please ask the kidney care team about this.

Most kidney patients will have more than one type of dialysis during their lifetime and it is possible to swap from one treatment to another if you wish.

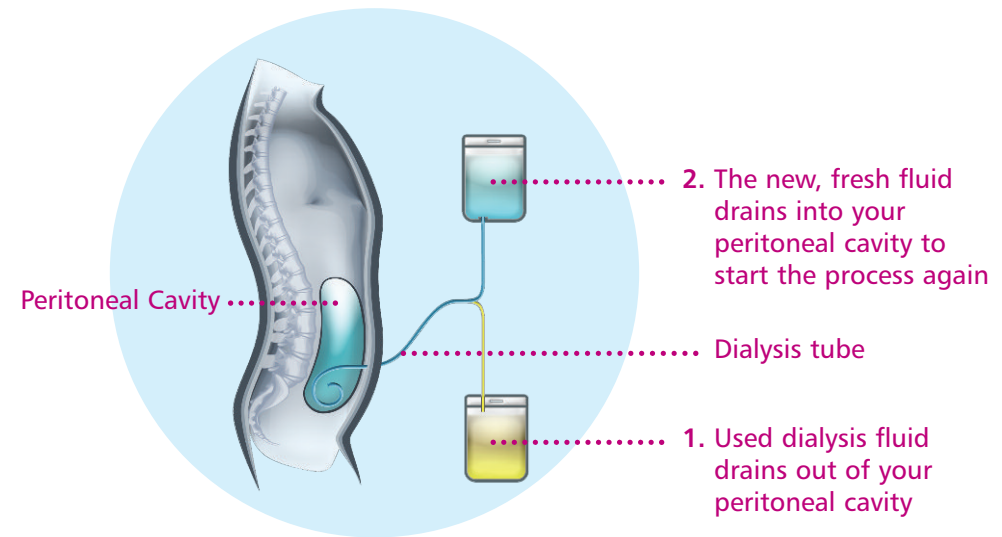
What is peritoneal dialysis?

This is a form of dialysis that we teach you to do yourself at home.

The peritoneum is a natural membrane (covering) lining your abdomen and surrounding most of your organs. It has two layers. Dialysis fluid is run into the peritoneal space (cavity) through a small, soft tube called a PD catheter or Tenckhoff Catheter. Waste products are passed from your blood, across your peritoneum and absorbed into the dialysis fluid. When the fluid is drained out again it takes waste and extra fluid out of your body.

The fluid needs to be changed regularly, this is known as an "exchange". Dialysis is happening all the time because there is always fluid left in your abdomen.

Peritoneal dialysis (PD)



You will need a small operation to insert the PD catheter. Many people stay in hospital overnight, but you may be able to go home the same day. This is usually done two to four weeks before you need to start dialysis.



There are two types of PD: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Automated Peritoneal Dialysis (APD).

- **CAPD** – exchanging fluid four times a day by hand.

Continuous – means you are dialysing all the time.

Ambulatory – between exchanges of dialysis fluid you can carry out your everyday activities.

Peritoneal – using the peritoneal cavity.

Dialysis – the process by which waste products and fluid are removed from your body.



Photographs courtesy of Baxter Healthcare Ltd

- **APD** – exchanging fluid during the night using a machine.

Automated – a machine performs the exchanges overnight while you sleep.

Peritoneal – using the peritoneal cavity.

Dialysis – the process by which waste products and fluid are removed from your body.



What are the risks associated with PD?

- **Peritonitis**: this is an infection of the peritoneal membrane – the lining of the peritoneal cavity where the fluid sits. We will teach you how to reduce the risk of peritonitis and what to do if you think you have it. Usually peritonitis can be treated successfully with antibiotics at home but sometimes people need to be admitted to hospital for treatment. If the infection is very severe,

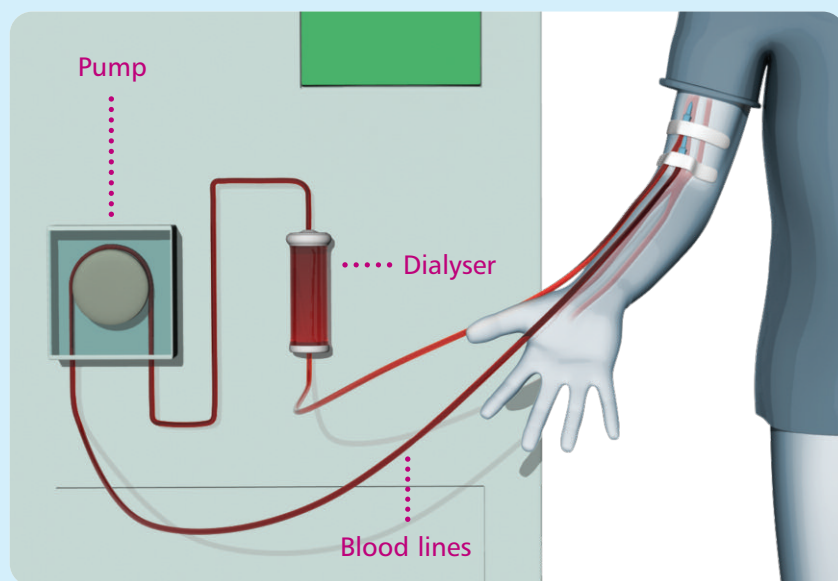
peritoneal dialysis may be stopped and you will need to swap to haemodialysis either temporarily or permanently depending on the severity of the infection.

- **Infection where the catheter comes out of your abdomen**: known as the exit site. This can usually be treated successfully with antibiotics but if severe, you may need to have the catheter removed and re-inserted in a different part of your abdomen.
- **Problems with draining the fluid out of your body**: we will teach you how to deal with this if it occurs.
- **Abdominal hernia**: a small number of people develop an abdominal hernia because of pressure caused by the dialysis fluid. A hernia is when an internal part of the body, for example an organ, pushes through a weakness in the muscle or surrounding tissue wall. If this happens you will need a small operation to repair the hernia and have temporary haemodialysis while the scar heals.
- **Constipation**: some people are prone to constipation and this can cause problems with drainage the fluid out of your body, we will advise you on how to avoid constipation.
- **Pain and discomfort**: some people find PD is uncomfortable, or even painful, particularly when they first start treatment. Most people will get used to having fluid in their abdomen, but sometimes small people are unable to tolerate more than 1.5 or 2 litres of fluid. A feeling of 'fullness' or of being 'bloated' after eating is also common.
- Very rarely PD patients can develop thickening and scarring of the peritoneal membrane, called Encapsulating Peritoneal Sclerosis. This is thought to be related to staying on PD for a very long time. This can cause abdominal pain, difficulty absorbing nutrients, and in extreme cases can cause severe abdominal problems. To avoid this occurring we recommend that you stop PD after five years and start haemodialysis as an alternative treatment.

What is haemodialysis (HD)?

Haemo means blood. Dialysis means to clean. Haemodialysis can be done at a dialysis centre or we can teach you to do it yourself at home.

During HD, blood flows out of your body, round a dialysis machine, through a dialyser (artificial kidney), which cleans it and then it returns to your body. Only a small amount of your blood is out of your body at any one time.



You will need a small operation to form a fistula or graft (see opposite) or to insert a dialysis line.

A fistula is where an artery is joined to a vein so that the vein enlarges, enabling needles to be inserted into your bloodstream for HD. One to take blood out of your body and the other to put it back. The operation is usually done under a local anaesthetic as a day case. A fistula is usually done three to six months before you need HD because it needs time to enlarge.

In some people it is difficult to form a fistula, in which case a small piece of plastic is used to join the artery and vein. This is known as a graft.

If you need dialysis before your fistula is ready, you will need a dialysis line. This is a small plastic tube put into a large vein in your neck and is a day case procedure.



There are different ways of doing HD:

- **HD in a dialysis centre**, where the nurses carry out the HD. Our dialysis centres are managed by experienced nurses. Details of our centres can be found on pages 23-24.
- **Self-care HD in a dialysis centre**, where we teach you to carry out some or all of the HD. It can also involve learning more about living with kidney disease and staying healthy.
- **HD at home**, where we teach you to carry out the HD yourself at home, possibly dialysing overnight. We will teach you at our home dialysis training centre near Guy's Hospital or at The Tunbridge Wells Kidney Treatment Centre, this usually takes between four and 12 weeks. Someone will visit you at home to make sure you have enough space to store the machine and supplies. We will provide you with most of the equipment you need and also advise you of any changes which may have to be made to your home so you can dialyse there. There is no charge for delivery and disposal of supplies or for any reasonable adjustments made to your home.



What are the risks associated with HD?

- **Low blood pressure caused by the drop in fluid levels during HD:** low blood pressure can cause nausea and dizziness. This can be resolved by adjusting the fluid removal during treatment.
- **Infection of the dialysis line or fistula:** this can cause high temperatures and dizziness; it can be treated with antibiotics. If the infection is severe in a line, it may need to be removed and another one inserted.
- **Infection in the blood from the dialysis line or fistula:** this can cause high temperatures, dizziness and if severe can be life threatening, however it can usually be treated with antibiotics.
- **Muscle cramps,** usually in the lower legs. This is thought to be caused by the muscles reacting to the fluid loss that occurs during HD and can often be resolved by adjusting the fluid removal during treatment.
- **Itchy skin:** caused by a build-up of toxins (poisons) in the body between dialysis sessions. We can prescribe a medicine to help with this and dietary advice may also help.
- **Bleeding from the fistula:** if prolonged or severe you may need a blood transfusion and/or further surgery to the fistula.
- **Blockage of the dialysis line or fistula:** this may mean that the blood flow around the dialysis machine is poor making the treatment less effective. You would need to have some tests to assess the severity of the blockage and possibly an operation on the fistula or a new line inserted.



Where is my nearest dialysis centre?

Astley Cooper Dialysis Unit

5th Floor
Borough Wing
Guy's Hospital
Great Maze Pond
London SE1 9RT

Public transport links:

London Bridge rail/bus station. This centre is primarily for those who have health conditions requiring them to be treated within the hospital.

Borough Kidney Treatment Centre

46 Long Lane
London SE1 4AU

Public transport links:

London Bridge rail / bus station and Borough underground station.

Camberwell Dialysis Unit

Chartwell Business Centre
61-65 Paulet Road
London SE5 9HW

Public transport links:

Denmark Hill or Loughborough rail stations; local buses run close to the unit.

Forest Hill Dialysis Unit

107-113 Stanstead Road
Forest Hill
London SE23 1HH

Public transport links:

Forest Hill rail station; local buses run close to the unit.

This unit is expected to move into University Hospital Lewisham in 2017.

New Cross Gate Dialysis Unit

Unit A
Ewen Henderson Court
40 Goodwood Road
New Cross Gate
London SE14 6BL

Public transport links:

New Cross and New Cross Gate stations; local buses run close to the unit.

Sidcup Kidney Treatment Centre

Queen Mary's Hospital
Frogna Avenue
Sidcup
Kent DA14 6LT

Public transport links:

Sidcup rail station; local buses run close to the unit.

Where is my nearest dialysis unit? (continued)

Tunbridge Wells Kidney Treatment Centre

Abbey Court
7-15 St. Johns Road
Tunbridge Wells
Kent TN4 9TF

Public transport links:

Tunbridge Wells rail station; local buses run close to the unit.

How will I get to the dialysis centre?

We encourage you to walk or use public transport. If you are on a low income, you may be able to claim back the cost of travel. Some of the community dialysis centres have car parking available. The hospital can provide transport if your medical condition means that you are unable to use public transport. To find out more, ask for a copy of our leaflet about patient transport.

Can I stop dialysis?

There might come a time when you feel you want to stop dialysis. You might feel that it is no longer maintaining or improving your quality of life. You are encouraged to discuss this with your doctor, other members of your healthcare team and your loved ones before making a final decision.

Your kidney team will want to have a clear understanding of why you made this decision and to find out if they can make any improvements that will affect your decision. If you are thinking about stopping dialysis because of treatment or other medical problems, your doctor might be able to make some changes to improve your situation.

If you stop dialysis, you can live for one to two weeks, depending on the amount of kidney function you have left and your overall medical condition. If you feel any discomfort, you can be given medication.

Without your dialysis treatment, toxic wastes and fluid will build up in your body reducing your appetite, and making you feel nauseous and tired. The fluid build-up can make it more difficult for you to breathe but your doctor can prescribe medication to help with this.

Your kidney team can advise you about the type of care you might need, and help to arrange it, as well as provide emotional support to you and your loved ones. You can find out more information about psychological support on page 86.

If you are thinking about stopping dialysis, you may find the information provided by our leaflet *Choosing to stop dialysis* helpful. This can be provided by your team at the kidney clinic or dialysis centre.

More information

You can get more information about fistulas, home haemodialysis and self-care dialysis from the kidney team. You may also like to ask us for a copy of the film *Living life to the full on dialysis*. This is available online at www.mykidney.org.uk.

What can I do?

- If you are thinking about home dialysis, arrange to meet the home dialysis team
- If you are thinking about haemodialysis, arrange to visit a haemodialysis centre
- Watch the film *Your kidneys, your choice* to find out more about your treatment options. This is available online at www.mykidney.org.uk
- Talk to a peer supporter – an experienced kidney patient
- Find out about the education sessions at the hospital
- Watch the film *Living life to the full on dialysis* to find out more about self-care dialysis options.

Questions you might like to ask

- How soon will I need to come into hospital for my dialysis catheter or fistula surgery?
- When will I start treatment?
- Is there a waiting list for my local haemodialysis centre?
- Can I visit my local haemodialysis centre?

Decision aid

The following table is designed to help you compare the different dialysis treatments and can be used to help you decide which treatments may be right, or not right, for you. It is important to remember that what suits one person may not suit another.

FAQ	Haemodialysis (HD) in a dialysis center	Self-care HD in a dialysis center	Haemodialysis (HD) at home	Continuous ambulatory peritoneal dialysis (CAPD) at home	Automated peritoneal dialysis (APD) at home
Is any surgery involved?	Yes, you will need a small operation to create a fistula or insert a dialysis line.	Yes, you will need a small operation to create a fistula or insert a dialysis line.	Yes, you will need a small operation to create a fistula or insert a dialysis line.	Yes, you will need a small operation to insert a peritoneal dialysis catheter.	Yes, you will need a small operation to insert a peritoneal dialysis catheter.
How long does it take?	The dialysis takes about four hours. It takes about 30 minutes to connect you to the dialysis machine and about 30 minutes to disconnect you at the end. This will need to be done three times a week on alternate days.	The dialysis takes about four hours. It takes about 30 minutes to connect yourself to the dialysis machine and about 30 minutes to disconnect yourself at the end. This will need to be done three times a week on alternate days. If you self care you will not be dependent on nursing staff so you are likely to have shorter waiting times.	You dialyse for at least 12 hours a week depending on what your body needs. Most people dialyse more often and/or for longer at home than in a dialysis unit as dialysing for longer usually means that you feel better and it reduces the risk of developing other medical conditions. You can also dialyse overnight instead of during the day.	CAPD takes about 20-30 minutes to drain the fluid out and in. You need to do this four times every day. You will also need to give enough time to set up before dialysis and to tidy up afterwards.	APD takes about 30 minutes to set up the machine. This needs to be done before you go to bed. You will be attached to the machine for approximately eight hours every night. You will also need about 30 minutes the next day to clean the machine and tidy up.
Does it hurt?	It might be uncomfortable at first when the fistula needles are inserted but most people get used to it quite quickly.	It might be uncomfortable at first when the fistula needles are inserted but most people get used to it quite quickly.	It might be uncomfortable at first when the fistula needles are inserted but most people get used to it quite quickly.	It might be uncomfortable at first but most people get used to it quite quickly.	It might be uncomfortable at first but most people get used to it quite quickly.
Can I choose the times that I dialyse?	The dialysis centres run on an allocated appointment system with several time slots throughout the day and early evening. Staff will try to give you an appointment time that meets your needs but this may not be possible at first as some times are more popular than others. The dialysis centres do not open on Sundays.	You will have more flexibility around your appointment times as you will not be dependent on nursing time. Most of our centres have a dedicated area for those who choose to self-care. The dialysis centres do not open on Sundays.	You will be able to fit dialysis around work, family and leisure time as long as you dialyse for at least 12 hours a week (depending on what your body needs). Some people choose to dialyse overnight.	CAPD is done four times every day. You can vary the times that you carry out the dialysis to some extent to fit around work, family and leisure time.	APD is done overnight and as long as you dialyse for about eight hours you can choose the times that you dialyse to fit around work, family and leisure time.

FAQ	Haemodialysis (HD) in a dialysis center	Self-care HD in a dialysis center	Haemodialysis (HD) at home	Continuous ambulatory peritoneal dialysis (CAPD) at home	Automated peritoneal dialysis (APD) at home
Will I be able to carry on working or studying?	Staff will try to arrange your dialysis times to suit your work or study needs but you may have to wait until a suitable appointment time becomes available.	With self-care you have more flexibility about when you dialyse. This should allow you to carry on working and/or studying.	You will be able to fit dialysis around your work and/or study.	You may need to do a CAPD exchange at work or college, you will need to arrange this with your employer or tutor.	APD is done overnight so you will be able to fit it around work and/or study.
Will I be able to go away on holiday?	It is possible to go away providing you are fit enough to travel. (see page 80)	It is possible to go away providing you are fit enough to travel. (see page 80) It is possible in some instances to take a HD machine away with you providing you self care. It is likely that a mobile HD machine will become available at some point in the near future.	It is possible to go away providing you are fit enough to travel. (see page 80) It is possible in some instances to take a HD machine away with you. It is likely that a mobile HD machine will become available at some point in the near future.	It is possible to go away providing you are fit enough to travel. (see page 80)	It is possible to go away providing you are fit enough to travel. (see page 80)
What can I eat?	There is some dietary advice you should follow to stop too many toxins from building up in your blood. (see pages 66-69)	There is some dietary advice you should follow to stop too many toxins from building up in your blood. (see pages 66-69)	There is some dietary advice you should follow to stop too many toxins from building up in your blood. (see pages 66-69) Most people dialyse more often and/or for longer at home than in a dialysis unit, this will usually mean that there are fewer dietary restrictions.	There is some dietary advice you should follow to stop too many toxins from building up in your blood. (see pages 66-69) With CAPD you are dialysing every day so this will usually mean that the dietary restrictions are fewer than with HD.	There is some dietary advice you should follow to stop too many toxins from building up in your blood. (see pages 66-69) With APD you are dialysing every day so this will usually mean that the dietary restrictions are fewer than with HD.

FAQ	Haemodialysis (HD) in a dialysis center	Self-care HD in a dialysis center	Haemodialysis (HD) at home	Continuous ambulatory peritoneal dialysis (CAPD) at home	Automated peritoneal dialysis (APD) at home
How much fluid can I drink each day?	This varies from person to person, to ensure that fluid does not build up in your body.	This varies from person to person, to ensure that fluid does not build up in your body.	<p>This varies from person to person, to ensure that fluid does not build up in your body.</p> <p>Most people dialyse more often and/or for longer at home than in a dialysis centre, this usually means that you can drink more freely.</p>	<p>This varies from person to person, to ensure that fluid does not build up in your body.</p> <p>With CAPD you are dialysing every day so this usually means that you can drink more freely than with HD.</p>	<p>This varies from person to person, to ensure that fluid does not build up in your body.</p> <p>With APD you are dialysing every night so this will usually mean that you can drink more freely than with HD.</p>
Do I have to do the dialysis myself/ will I need help from others?	The nurses will do the dialysis for you. You can learn to do some of the treatment yourself if you wish.	The nurses will teach you how to carry out the treatment yourself.	The home dialysis team will teach you how to carry out the treatment yourself. Some people have support from family, friends or a carer to assist them.	The home dialysis team will teach you how to carry out the treatment yourself. Some people have support from family, friends or a carer to assist them.	<p>The home dialysis team will teach you how to carry out the treatment yourself. Some people have support from family, friends or a carer to assist them.</p> <p>Having assisted APD means you connect your catheter to the PD machine yourself, but preparing the machine and disposing of used equipment is done by a nursing assistant who visits you at home every day.</p> <p>If you are physically unable to carry out the procedure yourself, we may be able to arrange some assistance for you.</p>

FAQ	Haemodialysis (HD) in a dialysis center	Self-care HD in a dialysis center	Haemodialysis (HD) at home	Continuous ambulatory peritoneal dialysis (CAPD) at home	Automated peritoneal dialysis (APD) at home
How often will I need to come to hospital?	You will need to attend the dialysis centre at least three times a week. You may also have to attend clinic appointments at the hospital if you need to see another member of the healthcare team.	You will need to attend the dialysis centre at least three times a week. You may also have to attend clinic appointments at the hospital if you need to see another member of the healthcare team.	You will be reviewed by the home dialysis team at the hospital every three months. You may have to attend additional clinic appointments if you need to see another member of the healthcare team.	You will be reviewed by the home dialysis team at the hospital every three months. You may have to attend additional clinic appointments if you need to see another member of the healthcare team.	You will be reviewed by the home dialysis team at the hospital every three months. You may have to attend additional clinic appointments if you need to see another member of the healthcare team.
Why might this dialysis treatment be right for me?	<p>In the dialysis centre, you may feel happier and more comfortable if you have help and support from healthcare staff and other patients.</p> <p>You will not need space at home to store equipment.</p>	<p>If you self-care, you will have more control and greater independence over your treatment.</p> <p>You can save yourself time as you don't need to wait for nursing assistance.</p> <p>Self-care can offer you more flexibility about when you dialyse. This might allow you to carry on working or have more leisure time.</p> <p>If you self-care you can then consider one of the home dialysis options which may suit your lifestyle better.</p> <p>Learning to self-care often leads to a greater understanding and management of your condition. This can benefit you in the long-term and ultimately improve your quality of life.</p>	<p>Having HD at home is a home-based treatment so you will have less travelling.</p> <p>If you wish you can dialyse overnight so that your day times are free.</p> <p>Most people can carry on working (depending on the nature of your job). You can fit dialysis around family and leisure time.</p> <p>You can dialyse more often and/or for longer, dialysing for longer usually means that you will feel better, you need fewer medications, can eat and drink more freely and it reduces the risk of developing other medical conditions.</p> <p>Learning to self-care often leads to a greater understanding and management of your condition. This can benefit you in the long-term and ultimately improve your quality of life.</p>	<p>Having CAPD at home is a home-based treatment so you will have less travelling.</p> <p>Most people can carry on working (depending on the nature of your job). You should be able to fit dialysis around family and leisure time.</p> <p>CAPD is similar to the way your kidneys work because it is happening all the time. This means that it puts less of a strain on your body.</p> <p>Learning to self-care often leads to a greater understanding and management of your condition. This can benefit you in the long-term and ultimately improve your quality of life.</p>	<p>Having APD at home is a home-based treatment so you will have less travelling.</p> <p>You dialyse overnight so your day times are free.</p> <p>Most people can carry on working (depending on the nature of your job). You should be able to fit dialysis around family and leisure time.</p> <p>APD is similar to the way your kidneys work because it is happening all the time. This means that it puts less of a strain on your body.</p> <p>Learning to self-care often leads to a greater understanding and management of your condition. This can benefit you in the long-term and ultimately improve your quality of life.</p>

FAQ	Haemodialysis (HD) in a dialysis center	Self-care HD in a dialysis center	Haemodialysis (HD) at home	Continuous ambulatory peritoneal dialysis (CAPD) at home	Automated peritoneal dialysis (APD) at home
Why might this dialysis treatment not be right for me?	<p>If you work or are studying you might find it difficult to fit this in with attending for dialysis at a dialysis centre, although we may be able to offer you an evening appointment.</p> <p>You will need to travel to a dialysis centre three times a week for dialysis.</p>	<p>At first you might not feel ready to do your own dialysis.</p> <p>Sometimes people start learning once they have been dialysing for a while.</p> <p>You might not be fit or well enough to consider self-care dialysis.</p> <p>You will need to travel to a dialysis centre three times a week for dialysis.</p>	<p>You might feel you need the support of nurses around you.</p> <p>You might not have enough room in your home for the dialysis machine and other equipment.</p> <p>You might not be fit or well enough to consider home dialysis.</p>	<p>CAPD needs to be done every day. You might not have enough room in your home for the dialysis equipment.</p> <p>CAPD may not be suitable for you if you have had major surgery on your abdomen (tummy) or have bowel disease such as diverticulitis, colitis or are very overweight.</p> <p>You might not be fit or well enough to consider home dialysis.</p>	<p>APD needs to be done every night. You might not have enough room in your home for the dialysis machine and equipment.</p> <p>APD may not be suitable for you if you have had major surgery on your abdomen (tummy) or have bowel disease such as diverticulitis, colitis or are very overweight.</p> <p>You might not be fit or well enough to consider home dialysis, although in some situations we can arrange for someone to assist you with APD.</p>

Having a Kidney transplant

A kidney transplant operation is when a kidney from one person is placed in the body of another person. A kidney can either be donated by someone who has died (a deceased donor) or from a living person.

If you are diabetic, you might be suitable for a combined kidney and pancreas transplant.

How do I know if I can have a transplant?

You will need to discuss the options open to you with your kidney team as early as possible so you can make the best decision for you and your family. If you feel you need more information at any time, please ask. You will also go through a series of tests to make sure that you are fit and healthy enough to have a transplant.

Why you might be suitable for a transplant

- For many patients with kidney failure a transplant is the best treatment choice, giving you the best chance of having a lifestyle similar to the time before you became ill.
- A transplant is also the treatment option that is most likely to improve your long-term health.

Why you might not be suitable for a transplant

- If you have other conditions as well as kidney failure, for example significant heart or lung disease, you may not be fit enough for a transplant operation because the risks would be much greater than the potential gains.
- If you are obese, the risks of having a transplant operation may be too great and technically difficult. The hospital can give you support to lose weight. See Chapter 8.

What is tissue typing and cross matching?

If you have a kidney transplant, you will need to take anti-rejection medication to stop your body's immune system from recognising the kidney as foreign and destroying it. Your body recognises the kidney as foreign partly because of characteristics called the tissue type. If your **tissue type** is similar to the person donating the kidney then your body is less likely to reject the kidney.

The **cross match** is the final blood test before a transplant operation happens. It checks if you have any antibodies to the donor kidney, which could damage or destroy it. The operation can only go ahead if the result of the cross match is negative.

What are the different types of kidney transplant?

● Deceased donor transplant –

A deceased donor kidney comes from someone who has died. There is a national pool of people waiting for this type of transplant. You can find out more in the leaflet *Understanding the kidney transplant pool*. Please ask us for a copy.

● Living donor transplant –

Most people can live a normal life with only one of their two kidneys. Some choose to donate one of their kidneys to a family member or a friend. This is called living kidney donation. You can find out more from the booklet *Gift of life*. Please ask us for a copy.

● The UK Living Kidney Sharing Schemes –

If a family member or friend would like to donate a kidney to you, ideally they should be compatible with you in terms of blood group and tissue type. If they are not this is known as an 'incompatible' or 'mismatched' transplant. If the person still wants to donate and is healthy, you could be paired with one or more incompatible donors and recipients in the same situation so that each donor can donate their kidney to the other donor's recipient. Each recipient benefits from a compatible transplant that he or she would not otherwise have had. Where two couples are involved this is known as a 'paired' donation and where more than two pairs are involved, this is known as a 'pooled' donation.

- **Altruistic donation –**

This is where a person volunteers to donate a kidney to an unknown recipient. The benefit of this type of donation is that a person in the transplant waiting pool receives a living donor kidney and the number of patients waiting in the pool is reduced. This increases everyone's chances of receiving a kidney.

- **ABO and HLA incompatible transplantation –**

An ABO (blood group) incompatible transplant takes place between a living donor and a recipient with a different blood group.

An HLA (Human Leukocyte Antigen) incompatible transplant takes place between a living donor and a recipient who has a different tissue type.

- **Kidney and pancreas transplantation –**

This may be an option if you have diabetes and kidney failure.

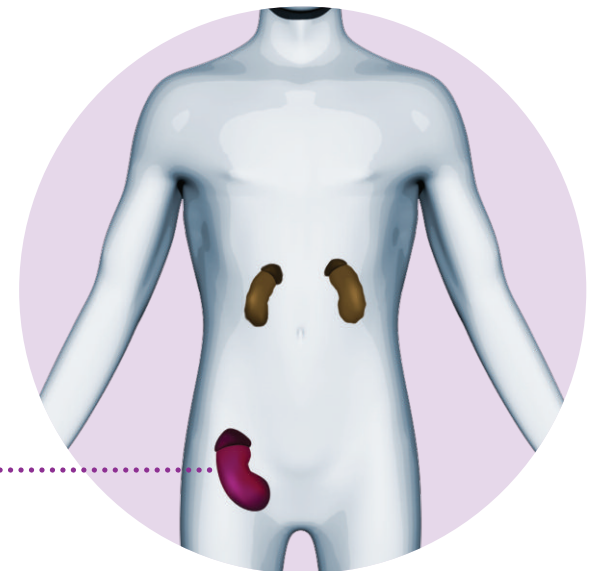
The transplant operation takes between two and four hours. The transplanted kidney is usually put in on the right side of your groin/pelvic area (see picture opposite) but it can also be transplanted on the left side. The exact positioning varies according to the individual patient.

The blood vessels of the donor kidney are attached to your blood supply, and the ureter (the tube which connects the kidney and the bladder) is joined to your bladder. The operation will leave you with a scar which will fade over time. Your kidneys are not usually removed.

A narrow tube called a stent is put down the ureter to protect the join with your bladder. Once you have healed, you will need a small procedure between four to six weeks after your transplant to take the stent out.

What are the benefits of having a transplant?

- Having a transplant means that you do not have to rely on dialysis.
- You might find you have more energy, making you feel more able to cope with everyday life, including work or studies.
- Your sex life and fertility will probably improve (if it has been affected by having kidney failure).
- If you have insulin dependent diabetes and have a kidney and pancreas transplant, you should no longer need to take insulin to control your blood sugar.
- You will not need to travel to hospital for dialysis. However, you will need to come to hospital every week for clinic appointments for up to six months after your transplant. After this time you will attend clinic less often.
- You will have a less restrictive diet than if you are on dialysis, but you should continue to eat healthily.



Transplanted Kidney

- You do not need space at home to store equipment.
- You will be able to restart any sport or exercise after the transplant, although if you play contact sports please discuss this with your kidney doctor or nurse first. You must be a healthy weight for the operation so exercise is important while you are waiting for a transplant.

What are the risks in having a transplant?

- There are the general risks associated with having surgery and a general anaesthetic, including the risk of infection. These will be discussed in more detail as part of the education and consent process.
- There is always a risk your body will reject the transplanted kidney. This means the body's immune system recognises a transplanted kidney as foreign and tries to attack it. Therefore you will need to take anti-rejection medication for the rest of the time the kidney is working. You may have side effects with this medication, such as excess weight gain, hair growth and an increased risk of some cancers, including skin cancer. Many of these can be prevented by carefully following the advice of the healthcare team. It is especially important that you do not stop taking any medication without first talking to your kidney team.
- You are also more susceptible to infection after a transplant because of the medication.

How do I know if I'm in the transplant pool?

If you are unsure, please ask the nurse or doctor when you come to clinic.

How can I find out if someone is a suitable donor?

If you wish to consider living kidney donation, please discuss this with the doctor or nurse at your next clinic appointment. It is not always necessary for the donor and recipient to have the same blood group.

Anyone wanting to donate a kidney will need to have a thorough assessment to make sure that they are fit and healthy enough to do so.

What if my donor is not compatible with me?

Blood tests will show whether your donor(s) is compatible. If the donor is not compatible with you this means that you, the recipient, have antibodies in your blood against your potential donor's blood group or tissue type.

We might be able to remove the antibodies from your blood by a process similar to haemodialysis which involves 'washing' the blood to make it safe to go ahead with the transplant. Or you might want to consider paired or pooled donation.

What is a pre-emptive transplant?

This means having a transplant before you need dialysis. This is usually from a living donor because it is possible to plan ahead so you receive a kidney when you need it.

Can I have another transplant if the first one fails?

Sometimes a kidney transplant fails. Most people can have further transplants if this happens. If your transplant fails, you might need to have an operation to remove the failed kidney. The success rate for subsequent transplants is generally as good as for the first. However, you are likely to wait longer. You will also need to go through the same tests again to make sure you are fit and healthy enough to have another kidney.

More information

Ask the kidney team for a copy of the booklet *Your guide to kidney transplantation* and *Gift of Life*.

What can I do?

- Talk to your family and friends about living donation.
- Talk to a peer supporter about what it is like to receive a transplanted kidney.
- Talk to us about your holiday plans as early as possible and keep your contact details up to date if you are in the transplant pool.
- Stay healthy – take your medication, eat a healthy diet and exercise regularly.
- Use sunscreen and do not stay out in the sun for too long.

Questions you might like to ask

- Am I in the transplant pool?
- How long will I have to wait for a transplant?
- How long will I have to stay in hospital?
- Who can donate a kidney to me?
- When will you consider doing a pre-emptive transplant?
- Are all transplants successful?

Supportive Care

If you are thinking about having a transplant or starting dialysis, you may not need to read this chapter. However, if you are unsure about whether dialysis or transplant are right for you and you have other serious health conditions, you might find the following information helpful.

What is supportive care?

It is reasonable for some patients to choose, after consultation with their kidney team, not to have dialysis. Having dialysis can be burdensome, and for some patients with other medical conditions it may not improve survival to any great extent.



With supportive care you do not have dialysis or a transplant and usually the failing kidneys will continue to get worse. The aim of supportive care is to maintain a good quality of life by prolonging kidney function for as long as possible, controlling symptoms, and supporting patients, their families and carers. Good planning for future healthcare needs and communication can help avoid inappropriate hospital admissions.

When you are managed supportively, there will be a core group of professionals involved in your care. This will include kidney and palliative care teams, your family doctor (GP) and district nurses. The aim is to ensure that you are cared for in a way that suits you and meets your needs.

The aim of supportive care is:

1. Preventing and treating the symptoms of kidney failure.
2. Protecting and maintaining remaining kidney function for as long as possible.
3. Establishing your wishes and preferences and planning for the future.

"I know it was the right decision not to start dialysis. I know the treatment may extend my life by approximately one year possibly two years, but I have had this time with improved quality of life. I am so much happier as a result of the support I am now receiving."

Mr J, 84 years

"In my view the transfer from the normal clinic to the renal supportive care clinic was so smooth. I feel I can ask anything in this clinic. I feel so much happier – the approach of the renal supportive care team is so personal and uplifting. I feel closer to the people looking after me. My whole family knows who to contact."

Mrs P, 74 years.

"The normal process is that I will die one day but the support I have had from the renal supportive care service means that I no longer worry about it. Of course I understand that I cannot be cured of my kidney disease but I am now able to cope with my condition."

Mrs W, 79 years

"Without the renal supportive care service life would be so much more difficult for the patients and their families. I feel it is not about the treatment you receive but the way care is delivered."

Mr P, 82 years

Preventing and treating the symptoms of chronic kidney disease

When your kidneys are no longer working properly, you start to experience symptoms caused by the build-up of toxins in your bloodstream. Symptoms can include:

- tiredness
- pain
- restless legs
- itching
- breathlessness
- sickness.

The symptoms can affect people in different ways. If symptoms do occur, they can usually be relieved by medical and/or non-medical treatments. It is important to tell the doctors and nurses looking after you if you are experiencing symptoms, so that they can be effectively treated.

Protecting and maintaining any remaining kidney function

The things that slow down the progress of kidney disease include:

- managing your blood pressure
- good blood glucose control if you have diabetes
- preventing you having too much fluid in your body.

As your illness progresses we will focus more on maintaining quality of life by controlling symptoms as they arise.

Planning for the future

This means thinking about how and where you want to be cared for when you become less well and at the end of your life. This might be your own home or a hospice.

Can I make an advance decision about treatment I do not want?

Yes, you can decide what treatment you do not want if, in the future, you are unable to make decisions yourself. Please ask your healthcare team for more information about doing this.

How long will I live?

This varies for each individual. There are many things that affect how long you will live, including if you have other illnesses and how well your kidneys are working. Your healthcare team will be able to discuss this with you in more detail and will explain the things that can affect this.

Can I change my mind once I have decided not to have dialysis?

Yes. We will support you in any decision you make. However, if you change your mind it might be because you are starting to feel unwell which may mean you need dialysis immediately. Starting dialysis in an emergency is not as easy as starting it in a planned way.

More information

What can I do?

- Talk to the renal supportive care nurse.
- Watch the film *Your kidneys, your choice* to find out more about all treatment options. This is available online at www.mykidney.org.uk
- Talk to your family and friends about your choice.
- Take time to make the decision.

Medications

This section gives you more information about the medicine commonly used by kidney patients. We will also answer some questions about prescriptions.



It is important to take your medication according to the instructions on the packet.

Please talk to your kidney team at the hospital, or your GP, before you stop taking any medication, even if you have side effects, as stopping suddenly can be harmful. There may be an alternative medication you can take.

On the next page are some of the main medications you may be taking. Please ask the healthcare team if you have any questions.

Anti-hypertensives (blood pressure tablets)

You might need anti-hypertensive tablets to lower your blood pressure, because prolonged high blood pressure can damage your blood vessels, heart and kidneys. This might mean you need a transplant or dialysis sooner. There are many different tablets available. Some of the most common ones prescribed for kidney patients are called doxazosin, atenolol, ramipril and irbesartan. Reducing your blood pressure will not make you feel better in the short-term. However, in the long-term, the tablets will help you to stay healthy.

Diuretics (water tablets)

Healthy kidneys are very good at producing the right amount of urine to match the fluid you take into your body when you eat and drink. Damaged kidneys are not so good at producing urine and this often means that fluid builds up in your body, causing swollen ankles, difficulty breathing and high blood pressure.

Diuretics are tablets which encourage your kidneys to produce more urine, making you go to the toilet more. The most common diuretic is furosemide. When taking diuretics it is important not to drink too much fluid because the medication will be less effective and you will need to take higher doses. There is more information in the section called Diet which starts from page 65.

Erythropoietin (EPO)

Erythropoietin is often known as EPO. It is a hormone which is produced by healthy kidneys. EPO stimulates the bone marrow to make red blood cells. When your kidneys are not working properly you do not make enough EPO and you become anaemic. You may then feel tired, weak, cold and generally unwell.

When your kidneys are not producing enough EPO we can give you artificial EPO injections. Some people have this when they are on dialysis and many are taught how to do it themselves at home. If it is difficult for you to do your own injections, or you do not want to do them, we can arrange for a district nurse to help.

Your healthcare team needs to monitor your blood results and blood pressure when you have EPO injections and they may ask your GP to help with this.

There are several brands of EPO available, including Mircera®, Aranesp®, Neo-Recormon® and Eprex®. If you have any questions, or want information about EPO and how to inject yourself, please talk to the anaemia nurse or renal pharmacist.

Iron supplements

Your body needs iron, folic acid and vitamin B12 to make red blood cells and prevent anaemia. There are many iron supplement tablets available and the most commonly used is called ferrous sulphate. However, people with kidney failure are often unable to absorb iron from their stomach. We prefer to give iron injections directly into a vein because it corrects the iron deficiency straight away.

Laxatives

These are mainly given to PD patients to prevent constipation as this can sometimes stop the catheter from draining properly. There are many different types including senna, lactulose and sodium docusate.

Phosphate binders

These help to control your phosphate levels. The medications are calcium carbonate (Calcichew®, Adcal®), calcium acetate (Phosex®), sevelamer (Renagel®) or lanthanum (Fosrenol®). These need to be taken up to 15 minutes before, or with, food. Reducing your phosphate levels can help to prevent itchiness and bone weakness, and may help reduce your risk of heart problems.

Sodium bicarbonate

These are given to help prevent the build up of acid in your body. As your kidney function decreases there is less acid in your urine causing your bicarbonate level to drop. A low bicarbonate level can be bad for your heart and can hasten the deterioration of your kidney function.

Statins (cholesterol tablets)

You might need statins to lower your blood cholesterol as high cholesterol can lead to heart disease. There are many different types of statins available including simvastatin, pravastatin and atorvastatin. A healthy diet and exercise can also help to lower your cholesterol.

Vitamin D

This helps control calcium in your body and protects your bones. The medication may be called alfacalcidol. You take this daily or weekly depending on the instructions.

When you start dialysis or have a transplant, your medication will change. Your healthcare team will tell you more about this.

Hepatitis B vaccination

All kidney patients who need dialysis are at a slight risk of getting hepatitis B. This is a viral infection spread through infected blood or bodily fluids. It is advisable for all kidney patients to have hepatitis B vaccination. This is a safe vaccine which is given as four injections over six months. It is important that you have all four injections. Ask a kidney doctor or nurse or your GP for more information about the hepatitis B vaccine.

Can I take over-the-counter medications?

Over the counter (OTC) medications are ones you can buy from a pharmacy/chemist or supermarket without having a prescription from your doctor.

It is particularly important to avoid a type of painkiller called a non-steroidal anti-inflammatory drug (also known as NSAID), such as ibuprofen (brands include Nurofen®) as these can cause further kidney damage. Paracetamol is a safer alternative painkiller.

Always speak to the pharmacist and explain that you have kidney failure before buying over-the-counter medications. Please also let them know what medications you are taking so that they can check that they do not interact with any OTC medicines that you may wish to take.

Can I use complementary therapies?

Talk to your GP or doctor/nurse at the kidney clinic before you start taking any complementary medicines or herbal remedies. This is because they may interact with your other medicines, cause side effects which can make your condition worse or contain other unlabelled substances such as potassium or sodium which may be harmful to you.

Where do I get a repeat prescription?

Your GP will be able to prescribe most of your medications but some are only available from the hospital. If this is the case we will explain how to get repeat supplies. You should ensure you never run out of your prescribed medications.

Do I have to pay for my prescriptions?

You might be able to get free prescriptions if you:

- receive certain benefits/are on a low income
- have a fistula for haemodialysis
- are under 16 or aged 16-18 and in full-time education
- are aged 60 or over
- have a valid medical exemption certificate. These are issued on application to people with diabetes mellitus or have a fistula for haemodialysis requiring a continuous surgical dressing. To apply for a medical exemption certificate ask your doctor for an FP92A form.

There are other reasons why you may get free prescriptions. You can find out more by speaking to your local pharmacist or visiting www.nhsbsa.nhs.uk

What is a prescription pre-payment certificate (PPC)?

Kidney patients often have to take a lot of medication so it may be cheaper to buy a prescription prepayment certificate (PPC) – effectively a prescription 'season ticket'. A PPC covers you for all of your own NHS prescriptions no matter how many items you need. Your local pharmacist can give you more information.

More information

What can I do?

- Bring all your medications, or a list of them, to every hospital appointment.
- Take all your medications, or a list of them, if you are going to see your local pharmacist or your GP.
- Do not stop taking your medications without talking to your GP, kidney doctor or nurse.
- If you are given a one-off course of medication, finish the course.
- Have all four Hepatitis B injections – ask the nurse if you are not sure.

Questions you might like to ask

- Can I get free prescriptions?
- How often do I have to take my medications?

Understanding your blood results

This chapter covers some of the blood results which are most relevant to you. It includes information about what the results mean and a rough guide to the normal range. Your blood results will change as your kidney function alters.

Estimated glomerular filtration rate or eGFR

Your kidney function will be measured using estimated glomerular filtration rate or eGFR. This is the rate at which blood is filtered by the kidneys and can be referred to as the percentage of normal kidney function. The normal is about 100 in young adults. Kidney function decreases with age so many healthy people in their 80s will have an eGFR of 40-50.

This table shows the likely treatment you will need depending on your eGFR results.

eGFR	CKD Stage	Treatment
90 – 100	Stage 1	<ul style="list-style-type: none"> ● Annual blood, urine and blood pressure tests ● Adopt healthy lifestyle
60 – 90	Stage 2	<ul style="list-style-type: none"> ● Annual blood, urine and blood pressure tests ● Adopt healthy lifestyle
30 – 60	Stage 3	<ul style="list-style-type: none"> ● Annual blood, urine and blood pressure tests ● Adopt healthy lifestyle
15 – 30	Stage 4	<ul style="list-style-type: none"> ● Regular attendance at kidney clinic ● Start learning about treatment choices for kidney failure
Less than 15	Stage 5	<ul style="list-style-type: none"> ● Start treatment for kidney failure: dialysis, transplant or supportive care

Bicarbonate

acceptable range:

21-30mmol/L

When kidneys do not work properly, acid can build up in your body. This can cause the bicarbonate level in your blood to drop which is bad for your heart and may also hasten the deterioration in your kidney function. This can be treated with medications.

Calcium

normal range:

2.2 – 2.55 mmol/L

Calcium is important for healthy bones and so your nerves and muscles work properly. High and low levels of calcium can be harmful to your bones and your heart. You may be prescribed medications to keep your bones healthy.

Cholesterol

normal range:

less than 5mmol/L

Cholesterol is a fatty substance found in the body. Increased cholesterol levels can cause narrowing of the blood vessels.

Ferritin

normal range:

greater than 150ug/L

Ferritin is the amount of iron you have in your body. You need iron to make red blood cells and keep your Hb at the correct level.



Haemoglobin (Hb)

normal range:

120 – 150g/L for women and

130 – 170g/L for men.

For kidney patients target range is 100g/L – 120g/L

Hb is a measure of how many red blood cells you have in your body. If you are anaemic you will have low levels of Hb which can make you tired and short of breath. In CKD if your Hb level falls to 100g/L, treatment to correct anaemia will be recommended.

Phosphate

normal range:

0.9 – 1.4mmol/L

Phosphate is a mineral found in your body and in many foods. In kidney disease, your blood phosphate levels can rise which can cause weak bones, itching and problems with blood vessels, joints or muscles. It may be necessary to reduce the phosphate in your diet. Phosphate-binding medication may also be prescribed to help lower phosphate levels.

Potassium

acceptable range:

3.5 – 5.5mmol/L

Potassium is a mineral found in your body and in many foods. Your kidneys control the amount of potassium in your blood. In kidney disease, you lose this control. Too much or too little potassium can affect your heart beat, so you may be advised to decrease or increase (less common) the potassium in your diet.

PTH (parathyroid hormone)

acceptable range: 10-65 ng/L

This is a hormone made by small glands in your neck which helps in the control of calcium and phosphate in your body. PTH levels can rise in kidney disease and this can result in problems with your bones and bone pain. You may be prescribed medications to help control this.

If you have any concerns about your blood results, please do not hesitate to ask a member of the kidney team for advice.

More information

PatientView

PatientView is a free online resource. If you register at the kidney clinic you will receive a username and password that will enable you to see your individualised blood test results online. It also provides information about kidney conditions and treatments. www.patientview.org

What can I do?

- If you want to know more, ask about your blood results when you come to clinic.
- If you have access to a computer, register for PatientView so that you can view your blood test results online.

Questions you might like to ask

- What stage of kidney disease am I at?
- Do I need to see the dietitian?

Diet

Diet is an important part of your treatment for kidney failure. You will see a specialist kidney dietitian during your treatment. Your diet might change several times as your general condition and treatment changes.

Why is my diet important?

A balanced diet will help:

- ensure that the build-up of waste products in your body is limited
- ensure that you do not have too much salt or water in your body
- enable you to keep to a healthy weight and prevent you becoming malnourished or overweight.



How can a kidney dietitian help me?

A kidney dietitian will give you individual advice about your diet, based on your blood results, diet, weight, lifestyle, and treatment choice. The advice will focus on:

- having a well-balanced diet containing all the nutrients your body needs to be healthy
- foods you may need to restrict or avoid, and cooking methods to prevent the build-up of excess waste products in your body
- how to keep to your daily fluid allowance (if recommended)
- how to eat well if you have a poor appetite and ways to prevent malnutrition.

What do kidney dietitians look at in my diet?

Energy

Energy is important so that you can carry out your daily activities. Most of your energy (calories) should come from starchy carbohydrates, such as cereal, bread, potatoes, rice, noodles, pasta, cassava and yam. You should have at least one of these foods in every meal.

Protein

Protein is needed for growth and repair of muscle tissue. The richest sources of protein are animal protein foods such as meat, poultry, fish, yoghurt, eggs, cheese and milk. Vegetable protein foods include nuts, pulses (beans and lentils), tofu, Quorn and soya chunks/mince.



Fat

Eating less fat can help reduce your risk of heart disease and prevent you from becoming overweight. Saturated (bad) fats are found in butter, cheese, fatty meats, biscuits, cakes and pastries. Unsaturated (good) fats are found in olive oil, rapeseed oil, sunflower oil and spread made with these oils. Remember, all fats are high in energy so, if you are overweight, you need to limit all the fats that you eat. However, if you have a small appetite, fat is a good source of energy.

Fibre

Fibre keeps your bowel habits regular and keeps you feeling fuller for longer, which helps to prevent unnecessary snacking. Good sources of fibre include wholemeal/wholegrain breads and cereals, brown rice/pasta, fruit, vegetables, oats and pulses (beans and lentils).



Salt (sodium)

Too much salt can raise your blood pressure and can make it difficult to control the fluid in your body, as it makes you thirsty. Reducing the amount of salt in your diet will make this much easier. Most of the salt we eat is found in processed foods such as soups, salted snacks, processed meats and some breakfast cereals. Avoid adding salt to your food while cooking or at the table. Do not use salt substitutes such as *LoSalt* or *Solo* as these contain potassium (see below).

Potassium

Potassium is a mineral found in your body and in many foods. Your kidneys control the amount of potassium in your blood. In kidney disease, you lose this control. Too much or too little potassium can affect your heart beat. Hence, you may be advised to decrease or increase (less common) your dietary potassium intake. You do not need to follow a low or high potassium diet unless you have been advised to by the kidney team.

Phosphate

Phosphate is a mineral found in your body and in many foods. In kidney disease, your blood phosphate levels can rise which can cause weak bones, itching and a build-up of phosphate in your blood vessels, joints or muscles. This can cause them to harden. If your phosphate levels rise, the dietitian will advise you on how to reduce the phosphate in your diet. Phosphate-binding medication will also help lower your phosphate levels.

Fluid

As your kidneys fail, they are unable to control the amount of fluid in your body. Fluid can build up causing your ankles or legs to swell and making you short of breath. It can also increase your blood pressure. In the long-term, this will damage your heart. Once you start dialysis, you will need individualised advice about the amount you can drink each day to ensure that fluid does not build up. Eating less salty foods will reduce thirst and thus help you to keep to your fluid allowance.

What can I do if I have lost my appetite?

If your appetite is poor, it is important that you do not lose too much flesh weight (muscle or fat) because this can weaken your muscles, slow down healing and take you longer to recover from illness.

- Try to eat little and often. Eat smaller portions at mealtimes and have a snack between meals, such as toast, crumpets, biscuits, crackers or cake.
- Avoid filling yourself up with high fibre and low calorie foods which give you little energy, such as soup, fruit and vegetables.
- Avoid drinks with meals as they will fill you up very quickly.

What can I do if I am overweight?

If you are overweight and have a good appetite, you should aim to lose some weight. Remember that the amount of food you eat, as well as the type of foods, is important. The benefits of a healthier weight include having more treatment choices. You may not be able to have a kidney transplant if you are overweight because of the pressure the operation will put on your body. The dietitian can help you lose weight while maintaining a healthy diet.



More information

What can I do?

- Follow a healthy, balanced diet. Reduce the amount of salt you eat.
- Be aware of the amount of fluid you drink.
- If prescribed, take your phosphate binders as instructed.
- Exercise regularly. Even gentle walking will help.
- If you are going to see the kidney dietitian, bring along the person who does the cooking and food shopping.



Questions you might like to ask

- Do I need to lose weight?
- What is my ideal weight?
- How much fluid can I drink each day?
- How can I reduce the salt in my diet?
- Where can I get recipe ideas?

Healthy living

As you have a long-term health condition it is really important to keep well.



I have kidney failure, does this mean I will get other illnesses?

You might get some other illnesses such as:

Anaemia – this means your body is short of red blood cells, which carry oxygen round the body. If you are anaemic, you might feel breathless, tired, irritable and have pale skin, poor appetite and low sex drive. You might have some or all of these. Anaemia can be treated with EPO and iron injections.

Heart disease – kidney patients are at risk of developing heart disease but it is possible to reduce the risk by keeping your blood pressure down (this will usually involve taking medications). You should aim for a blood pressure at or below 130/70 when measured at the clinic or by your GP. Giving up smoking, taking regular exercise, reducing the amount of alcohol you drink and eating a healthy diet also help look after your heart.

Reduced bone strength – this can be caused by high phosphate levels, lack of calcium, not enough vitamin D and/or other medication. These can all be treated by reducing the amount of phosphate in your diet and taking prescribed tablets. If you have back pain or pain in your joints, such as your knees or elbows, it is important to talk to a doctor or nurse about this.

Gout – this causes severe pain in one or more of your joints, usually your big toe. The inflamed joint becomes swollen, and your skin can become red and sore around the affected area. We can treat you with prevention tablets, such as allopurinol, and treatment tablets, such as colchicine. Please do not take non-steroidal anti-inflammatories (NSAID) as this will make your kidney function worse.

Can I drink alcohol?

The NHS advises that men and women do not regularly drink more than 14 units a week.

Fourteen units is equivalent to six pints of average strength beer or 10 small glasses of low strength wine.

Regularly drinking above recommended levels can cause serious health problems. Also, the amount of fluid or potassium in some drinks can be of concern. Contact your GP for advice about local alcohol support services.





Should I stop smoking?

Yes! Smoking harms your heart and increases your risk of developing several types of cancer, lung disease and heart disease. Stopping smoking at any age will improve your health and may increase your life expectancy. Please ask for advice on how to stop smoking from:

- your GP
- your kidney team
- Trust stop smoking service on 020 7188 0995
- Smokefree National Helpline 0300 123 1044.

Can I do exercise?

Yes, living an active lifestyle is important for people of all ages. Kidney failure can make you feel tired and weak, and you may get breathless when walking up hill or climbing stairs. This can make physical activity feel difficult. It is important to maintain your fitness and muscle strength so that you are able to continue with all your day to day activities and continue doing the things that you enjoy.

Exercises against resistance (such as gravity or weight) carried out regularly will lead to stronger muscles over the course of six to eight weeks. Increasing daily activities (such as walking) by a little each week can help to improve your fitness and also reduce your risk of other common diseases such as diabetes, high blood pressure, cardiovascular disease, obesity and depression. When walking for exercise, try to maintain a speed where your breathing is a little quicker than normal.

Before starting any new exercise, please speak to the kidney team for personal advice, particularly if you use peritoneal or haemodialysis.



How can I get more information about exercise?

You can ask your kidney team or you can speak to your GP for advice on services available in your local area. Your GP may be able to refer you to an exercise programme locally.

Renal rehabilitation is a course of exercise available at Guy's Hospital over a 12 week period. It is run by qualified physiotherapists and aims to support you in becoming more active. If you want more information please speak to the kidney team.

Why is it important for me to be a healthy weight?

Being too heavy means that you may not be able to have a transplant or peritoneal dialysis (PD). If your BMI is more than 30, you might have more complications during the transplant operation and you will tend to take longer to heal. Once you have lost enough weight you might have more treatment choices. Staff in the kidney clinic or in your GP's surgery can advise you on what your weight should be. You can also calculate it yourself using the body mass index (BMI) calculators. There are a number of BMI calculators available on the internet or in healthy eating booklets.

More information

What can I do?

- Have your blood pressure checked regularly and take your blood pressure medication if your doctor has prescribed it
- Work out your body mass index (BMI)
- Take all prescribed medications
- Eat healthily, take regular exercise, give up smoking and reduce your alcohol intake
- If you are diabetic, get your diabetes under control.

Questions you might like to ask

- Can you suggest any exercise I can do?
- How much alcohol is it safe for me to drink?
- Where will I get repeat prescriptions?
- What is my target blood pressure?



Can I carry on working?

Yes, we encourage you to carry on working, if possible. This may be more difficult for some people than others, depending on the type of job you do and how you feel. You might want to reduce your working hours, or change your role, until you have started dialysis or had a transplant.

When deciding which treatment option to choose, it is important to consider how it will fit in with your job. If you are considering Continuous Ambulatory Peritoneal Dialysis (CAPD), you might want to think about how you will do an exchange at work. You might be able to get CAPD supplies delivered to where you work as well as to your home. Please talk to your employer and the PD team about the options.

If you are thinking about Haemodialysis (HD), consider what dialysis times will best fit around your work. Some centres offer evening appointments or you could consider home haemodialysis.

If you decide to stop working, it is important to find out about benefits you might be able to claim before you leave.

Can I carry on studying?

You should be able to carry on with your studies. However, you might want to change to a part-time, open or distance learning course. Talk to your tutor about your options.

Can I claim benefits?

You might be able to claim one or more benefits. Before stopping work or reducing your hours it is important for you to get financial advice. For more information read the leaflet *Know your benefits* which is available from the National Kidney Federation. You can also get advice from your local Citizens Advice Bureau (CAB).

Can you help me with housing?

We can offer advice if you are having problems with your housing because of your health. If you would like to dialyse at home but your home is not suitable, we can support your application to be re-housed. However, the final decision sits with the housing departments.

Will my illness affect my insurance?

Most insurance companies do not cover pre-existing conditions. Please read the small print carefully. If you have problems getting insurance, contact an insurance broker for advice.

You can get more information about insurance from The National Kidney Federation.

Can I still drive?

Many kidney patients continue to drive. If there is any other medical reason why you should not drive, contact the DVLA for advice. If you have a kidney transplant planned, you need to tell your insurance company, and cannot drive for at least a month after the operation.

Can I get a Blue Badge (parking for people with a disability)?

Kidney patients do not have an automatic right to have a Blue Badge. You might be eligible for one because of other medical problems or disabilities. Contact your local council for more information or visit: www.gov.uk/apply-blue-badge



Can I go on holiday?

You can still go on holiday. However, before making any holiday plans please talk to your kidney doctor or nurse to ensure you are fit enough to travel and to discuss any vaccinations you may need. Our leaflet *Dialysis away from base* explains how to arrange holiday dialysis. Please ask us for a copy.

If you are travelling out of the UK, it is vital to ensure you have full travel insurance in case you become unwell.

How will having kidney failure affect the way I look?

People with kidney failure sometimes have concerns about how they look. If you have dialysis you will need to have a fistula, dialysis line or PD catheter. If you have a transplant, you will have a scar, although this will fade with time. Sometimes people feel self-conscious about this. Please talk to your healthcare team if you have any worries or concerns.

I am not interested in sex any more, is this common?

You might find that you are more tired, feeling down and have less interest in sex. The medication you are taking might

also affect your sex drive. Men may experience difficulties getting and keeping an erection and in women orgasms may be less frequent. You may find it helpful to talk to someone – please do not be embarrassed to ask for advice. There are many effective treatments available. You will find more information about psychological support on page 86.

Will I still be able to have children?

If you are not yet on dialysis and have not had a transplant, becoming pregnant might make your kidney function worse. Women with kidney failure tend to be less fertile and might find it more difficult to get pregnant.

Women on dialysis are unlikely to become pregnant. However, it is still possible so it is very important to use contraception to avoid an unplanned pregnancy. Successful pregnancies are rare, but not unheard of, for women on dialysis.

Those with a well functioning transplanted kidney have the best chance of a normal pregnancy. We strongly advise women to wait at least a year after transplant before trying for a baby.



It is extremely important to talk to your doctor or nurse before trying for a baby to ensure that both your health and that of your baby are monitored.

Men with kidney failure are likely to have a lower sperm count. After a successful kidney transplant the sperm count usually increases.

Will my children have chronic kidney disease?

There are some kidney conditions which can be inherited. Ask your doctor about the cause of your kidney disease. If you are planning to have children, talk to your healthcare team about your concerns.

More information

Who can give me more information and support?

If you would like help with any of the issues in this chapter, please talk to your healthcare team.

Common feelings about chronic illness

You may feel different emotions or a change in how you see yourself. This is quite normal for most people who are facing a long-term medical condition for the first time in their lives, and can affect their family members and carers. Making a decision about treatment options can also be challenging.

Grief –

You might experience a period of grief, similar to losing someone special, your previous lifestyle or independence, or a change in work or leisure activities. If you feel this way, you may find that you gain more control and feel less sad by learning more about kidney failure.

Denial –

Patients sometimes find that denial helps them to cope with their diagnosis as they slowly come to terms with the condition and its impact on their lives. However, if you find you are not taking medication or missing dialysis appointments, you may need to seek support by seeing a counsellor or psychologist.

Guilt –

You might feel guilty about having a long-term condition and its impact on others. Many patients feel like this at different times over the course of their treatment. This is normal, and feelings of guilt may be addressed by seeking assistance from a counsellor or psychologist.

Anger –

You might feel angry about having kidney failure and how it affects your lifestyle, perhaps because you feel you have no control of the situation. By reading this booklet you are taking control and learning more about your condition. Feelings of anger may reduce as you gain more control over your health and the treatment.

Depression –

You might feel depressed. This may feel similar to grief but the signs include: problems with concentration and memory; feeling exhausted, restless or irritable; sleeping and eating too much or too little; lack of interest in things you normally enjoy. Depression can be treated with the help of a trained mental health professional.



Anxiety –

People with kidney failure may feel anxious. You may feel tense, uncertain and frightened, perhaps because you are being asked to make a decision about a treatment which will affect how you live your life. You may also feel anxious about other things in your life, such as your work or your family, and changes in your lifestyle.

If you are experiencing any of these emotions, it is important to talk to someone about them. Your healthcare team are happy to talk to you about any concerns or feelings you have. You can also talk to a counsellor or psychologist.

You might find it helps to write down a couple of questions and bring them along when you next come to hospital. No matter how trivial you think your question is, members of the healthcare team have experience with a wide range of issues and are always happy to advise you.

What support is available?

You can ask a nurse or doctor to refer you to the renal clinical psychologist. Your GP may also have a psychologist or counsellor in their practice or they can refer you to Improving Access to Psychological Therapies (IAPT) which is an NHS programme that offers psychological support for people with depression and anxiety.

We also offer Peer support which is support from another kidney patient. Peer support aims to provide practical, emotional and social support for people with kidney disease and their families. It gives you the chance to talk to an experienced kidney patient on a one-to-one basis. Relatives and carers can also talk to other relatives and carers of people with kidney failure. Ask a doctor or nurse for more information.

Your kidney team

You will come into contact with a range of kidney care professionals. Here is a list of the main people you may meet. Not everyone with kidney failure will meet all these people.

Clinical Psychologist –

supports you in adapting to your diagnosis or treatment plan. This may simply involve talking or might be a more problem solving approach, such as cognitive behaviour therapy.

Clinical Nurse Specialist

(CNS) – has specialised training and experience in caring for people with kidney conditions.

Dietitian –

gives you advice about how to achieve a well-balanced and practical diet suited to your needs. Advice may change regularly depending on such things as your level of kidney function, treatment choice and appetite. The dietitian can also give advice about reaching and maintaining your ideal weight before and after transplant.

Nephrologist/kidney doctor

– specialises in treating people with kidney conditions.

Occupational therapist –

supports you if you have difficulties with practical everyday tasks, such as dressing or getting in and out of the bath. They have specialist knowledge and can advise you on disability equipment and adapting your home and workplace.

Pharmacist – prepares and gives out medicines.

Pharmacists can also give a lot of information and advice about your medication.

Physiotherapist – advises patients about keeping fit and mobile. The physiotherapist can also give you advice on exercising.



Social worker – helps you and your family/friends adjust to changes in your lives by providing support, advice and information about issues including housing, benefits, work and getting help to manage at home.

Surgeon – you may meet a surgeon before you have a fistula formed or peritoneal dialysis catheter inserted. A surgeon will also perform your kidney transplant, although you may not meet him/her beforehand.

Technician – looks after the dialysis machines. You are most likely to meet a technician if you have home haemodialysis when they will provide advice and support with the equipment.

Glossary

This glossary provides brief explanations of some of the most common technical words and abbreviations used when talking about kidney failure and its treatment.

Anaemia –

a shortage of red blood cells in the body, causing tiredness, shortness of breath, loss of appetite and pale skin. One of the functions of the kidneys is to make EPO (erythropoietin), which stimulates your bone marrow to make blood cells. With kidney disease, your kidneys do not make EPO and you become anaemic.

Antibodies –

substances that normally help your body to fight infection. They are made by white blood cells. After a transplant, antibodies can attack the new kidney and cause rejection. Antibodies also cause some kidney diseases such as glomerulonephritis.

Arteries –

blood vessels that carry blood from your heart to the rest of your body.

Biopsy –

a kidney (renal) biopsy is a medical test that can identify the cause of your kidney problem. A tiny piece of tissue is removed from your kidney with a special needle and examined under a microscope.

Blood group –

an inherited characteristic of red blood cells. The common classification is based on whether or not you have certain antigens (called A and B) on your cells. People belong to one of four blood groups, called A, B, AB and O.

Blood pressure (BP) –

the pressure that your blood exerts against the walls of your arteries as it flows through them. One of the functions of your kidneys is to help control your blood pressure.

Body mass index (BMI) –

a measure of your weight relative to your height, which is associated with your body fat and health risk. If your BMI is more than 25, you are at risk of health problems. If your BMI is more than 30 you might have more complications during the transplant operation and you will tend to heal less well.

Diabetes mellitus –

a condition in which there is too much sugar in the blood. It can be treated by insulin, tablets or diet. It is the single most common cause of kidney

failure and usually occurs in people who have had diabetes for longer than ten years.

EPO –

abbreviation for erythropoietin (see below).

Erythropoietin –

a hormone, made by your kidneys, which stimulates your bone marrow to produce red blood cells. It can be given by injection.

Fistula –

an enlarged vein, usually at the wrist or elbow, that gives access to the bloodstream for haemodialysis. A surgeon creates a fistula by joining an artery to a vein in a small operation. This increases the flow of blood through the vein and causes it to enlarge, making it suitable for haemodialysis needles.

Graft –

a type of access for haemodialysis. A graft is a small plastic tube that connects an artery to a vein. It is inserted into your arm or leg by a surgeon. Haemodialysis needles are inserted into your graft during dialysis.

Peritoneum –

a natural membrane lining your abdomen and surrounding most of your organs. It has a very good blood supply and can be used as a filter.

Supportive management –

treatment of kidney failure without the use of dialysis or transplant.

Toxins (poisons) –

one of the main functions of your kidneys is to remove toxins from your blood (a process known as clearance).

Ultrasound scan –

this is a procedure that creates an image of an organ in the body.

Urea –

a substance made by your liver. It is one of the waste products from food that builds up in your blood if you have kidney disease. The higher the urea level, the worse the kidney disease.

Ureters –

the tubes that take urine from your kidneys to your bladder.

Urethra –

the tube that takes urine from your bladder out of your body.

Urine –

the liquid produced by your kidneys, consisting of the toxic waste products of food and the excess water from your blood.

Veins –

blood vessels which carry blood from your body back to your heart.

Vitamin D –

a chemical that helps your body to absorb calcium from your diet. If you have kidney disease, the level of vitamin D in your blood is usually low.

**More information
and support**



Further resources

Guy's and St Thomas' Kidney Patients Association

Tel: 020 7188 7552

E: info@gsttkpa.org

www.gsttkpa.org

Kidney Care UK (previously British Kidney Patient Association)

Tel: 01420 541 424

www.britishkidney-pa.co.uk

Kidney Research UK

Tel: 0845 070 7601

www.kidneyresearchuk.org

National Kidney Federation

Tel: 0845 601 0209

www.kidney.org.uk

NHS Blood and Transplant (organ donation)

Tel: 0117 975 7575

www.organdonation.nhs.uk

Diabetes UK

Tel: 0845 120 2960

www.diabetes.org.uk

Kidney services at Guy's Hospital

Kidney Clinic

4th Floor Tower Wing

Guy's Hospital

Great Maze Pond

London SE1 9RT

Tel: 020 7188 5664

Peer Support

Tel: 020 7188 0797

Clinical Psychologists

Tel: 020 7188 7845/9770

Social Workers

Tel: 020 7188 5684/4023

Online resources

Guy's and St Thomas' website

The kidney section provides information about our kidney and transplant services. All of our kidney and transplant information leaflets are listed here and can be read on-line or downloaded.

www.guysandstthomas.nhs.uk/our-services/kidney

My kidney website

This website has been put together by kidney patients and clinicians. It aims to help people understand more about kidney disease and how to live with it. www.mykidney.org.uk

PatientView website

PatientView is a free online resource for kidney patients. If you register at the kidney clinic you will receive a username and password that will enable you to see your personal blood test results online. It also provides information about kidney conditions and treatments. www.patientview.org

NHS Choices website

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

www.nhs.uk

This booklet is meant for information purposes only and does not replace the detailed discussions you have with healthcare professionals.

Language and Accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

Tel: 020 7188 8815

E: languagesupport@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

Tel: 020 7188 8801 (PALS)

E: pals@gstt.nhs.uk

Tel: 020 7188 3514 (complaints)

E: complaints2@gstt.nhs.uk

Guy's and St Thomas' NHS Foundation Trust

For more information about our services visit the Trust website:

www.guysandstthomas.nhs.uk

Switchboard: 020 7188 7188

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London SE1 7EH

Guy's Hospital

Great Maze Pond
London SE1 9RT