

Acute Services Division



Information about

Chronic Kidney Disease



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The purpose of this booklet

This booklet is for people with advanced Chronic Kidney Disease. The aim is to provide you and your family with information on the management of Chronic Kidney Disease. It may even generate more questions than it answers. However, it will help you discuss Chronic Kidney Disease and its treatment options – so please ask if there are any areas which you want to discuss.

The functions of healthy kidneys

Healthy kidneys act as filters to get rid of waste products which naturally build up in the bloodstream. These are taken out of the body when we pass urine. The amount of urine we pass helps to keep the amount of salt and water in the body at a balanced level.

The kidneys also produce a hormone called erythropoietin or (EPO) that helps in the production of blood cells. If you are lacking red blood cells you will become anaemic.

Other functions of the kidneys include:

- controlling the body's acid content,
- controlling blood pressure
- maintaining healthy bones.

So when the kidneys are not working all of these functions are affected.

What is Chronic Kidney Disease

We use the term Chronic Kidney Disease (CKD) for any disease that causes permanent damage to the kidneys over a long period of time. This makes the kidneys less able to work properly. Eventually treatment is needed to replace some of the work of the kidneys and maintain wellbeing.

Symptoms in Chronic Kidney Disease

Chronic Kidney Disease usually happens over a number of years. In the early stages of CKD there are usually no symptoms. For this reason it is often discovered either by chance (by blood tests) or later in the course of the condition when people start to get symptoms. These may include:

- Weakness and tiredness
- Itch
- Leg cramps
- Loss of appetite
- Nausea
- Shortness of breath
- Reduced fertility and sex drive

Management of Chronic Kidney Disease

When you have Chronic Kidney Disease it is likely that your kidney function will slowly get worse over a period of time. To start with the Renal Unit Team will manage your condition using medicines and carefully monitor your progress. The Renal Unit Team includes renal doctors, nurses, dietician, pharmacist and other health professionals.

The aims of managing CKD are:

- To delay the time when you will need to start dialysis for as long as possible
- To control some of the symptoms associated with Chronic Kidney Disease

To achieve these aims for as long as possible it is important that you:

- Attend clinics regularly – your visit will include the checking of your bloods
- Take all medicines which are prescribed
- Stop smoking (if you smoke)
- Eat a healthy diet following any advice from the dietician
- Reduce the amount of salt (sodium) you eat unless told otherwise
- Take regular exercise if you can

Patient access to results

Patients can access blood results, information on medicines and text from renal clinic letters using a secure and confidential system called “Patients Know Best” via the internet. If you are interested in accessing this system, ask a member of staff how to register or visit the web site for more information

🌐 <https://patientsknowbest.com/>

Kidney Replacement Therapy (KRT)

When your kidney function reaches a very low level you will usually need treatment to replace kidney function. For most people this would be when their blood tests measure kidney function at less than 10% (often at 5-7%). The treatment is either kidney transplantation or dialysis. These treatments are

called Kidney Replacement Therapy (sometimes shortened to KRT).

The Renal Team will normally start discussions about KRT options when they think it is appropriate, but feel free to ask about it at any time.

Kidney transplants and dialysis are described in more detail on the following pages.

Kidney Transplants

For suitable patients, kidney transplantation is likely to be the best renal replacement therapy option.

A kidney transplant requires an operation where a healthy donor kidney is placed in the abdomen. The donor and the patient receiving the kidney (the recipient) usually have compatible blood groups to reduce the risk of your body rejecting the new kidney.

A successful kidney transplant is the most effective treatment for established renal failure. All kidney transplants in the West of Scotland take place at the Queen Elizabeth University Hospital, Glasgow. Not everyone will be suitable for kidney transplantation.

There are two sources of kidney transplants:

1. The first is called Living Donation Transplantation. This is when someone offers to donate a kidney to another person. Usually this offer is from someone close to the person with advanced kidney disease, often a family member. This process takes several months if straightforward. If you think that this might be an option which you want to pursue, you should discuss it with your renal doctor who can start investigating whether this would be a possibility at an early stage. In some cases, it is possible to receive a living donor

transplant before you need to start dialysis. This is sometimes referred to as a “pre-emptive transplant”.

2. For suitable patients a pre-emptive transplantation is the best option. Sometimes a live donor may come forward who is not a suitable match. Live donation may still be possible via the National Kidney Sharing Scheme (NKSS). The team may discuss this with you at the clinic if clinically appropriate.
3. The other source of kidney transplants is from a donor who has died and donated their organs for transplantation. This is called a Deceased Donor Transplant. The waiting time for this type of transplant is usually lengthy and most people who get a deceased donor transplant will have been on dialysis for a period of time before they get a transplant. An estimate of the likely waiting time for deceased donor kidney transplant, is currently 2 years or longer.

After a kidney transplant you will need to stay in hospital for several days to recover from the operation. Some transplants do not work immediately after the operation and some patients will need dialysis for a period of time after the transplant.

Sometimes the body rejects the transplanted kidney. This happens because your body recognises that the new kidney is foreign and attacks it. We give immunosuppression medicines to all transplant patients to reduce the effect of rejection. These can have side effects, but are vital to protect the transplant.

After a successful transplant you will regularly visit the transplant clinic to monitor your progress and your kidney function.

Current UK statistics (2016) suggest that more than 90% (9 out of 10) of kidney transplants are still working after one year, more than 80% (8 out of 10) are still working after five

years and around 70% (7 out of 10) after ten years (NHSBT Activity Report 2011-12)

Some positive aspects of kidney transplantation

- Improved health and quality of life
- Freedom from dialysis
- Close to normal kidney function
- Flexible clinic follow up visits
- Improved fertility for women

Some potentially negative aspects of kidney transplantation

- Risk from having an operation
- Risk of rejection of the transplant
- Possible side effects of medication taken after transplant
- Requirement for lifelong immunosuppression

Dialysis

There are different types of dialysis:

- Peritoneal Dialysis
- Haemodialysis

Dialysis can take place either in your home or in hospital. It is possible to use either peritoneal dialysis or haemodialysis at home. For suitable patients the renal team are keen to support dialysis treatment at home

Peritoneal Dialysis

This type of dialysis treatment uses the body's peritoneal membrane as the filter through which waste products and water are removed from your body. To allow this to happen we insert a small soft plastic tube (called a PD catheter or a Tenckhoff catheter) through the abdomen during a short

surgical operation, which usually involves staying in hospital for about 2 days. The tube is inserted to allow dialysis fluid to be put in and drained out of the abdomen. After the operation about 15-20 cm of the plastic catheter remains outside the abdomen. The place where the catheter comes out from your tummy (called the exit site) will be positioned to make it fit comfortably under your clothing.

Peritoneal dialysis works by introducing sterile dialysis fluid into the abdomen through the PD catheter. The fluid is left in the abdomen for 4 - 8 hours (called the dwell time). The waste products and water cross from the bloodstream through the peritoneal membrane and into the dialysis fluid. When the dialysis fluid is drained from the body the waste products are removed with it. New dialysis fluid is then introduced into the abdomen and the dialysis process starts again.

Peritoneal dialysis can be done in two different ways and are both effective treatments:

1. APD (Automated Peritoneal Dialysis).
2. CAPD (or Continuous Ambulatory Peritoneal Dialysis)

After the catheter is in place it is usual not to use it for at least 10 days. After this period of time, or when it is appropriate to start dialysis we will ask you to attend the PD clinic to receive training from the specialist nurses on all aspects of caring for your catheter and performing your dialysis. This training usually happens as an out-patient and can take 1-2 weeks. After the training is complete you will be able to carry out your dialysis at home independently. The Peritoneal Dialysis (PD) team will provide ongoing support.

1. APD

Automated Peritoneal Dialysis uses the same principles as CAPD, but uses a machine to perform the exchanges. Dialysis takes place during the night using the machine to regulate the introduction, dwelling and draining of dialysis fluid. This allows

patients to connect to the APD machine at bed time and receive dialysis while asleep. This treatment usually takes about 9 hours. To receive enough dialysis some patients on APD need to do one extra manual CAPD exchange during the day. APD machines are safe and straightforward to operate.

Assisted APD

For those that are keen for APD, but don't think they would manage this treatment by themselves, we can offer some assistance with setting up their machine during the day, however, we would not be able to help with connecting and disconnecting from the machine, before and after treatment.

2. CAPD

To perform CAPD you need to change the fluid in the abdomen (called a bag exchange) regularly each day. Most patients need to do 4 bag exchanges each day. You must do this in a clean environment using the techniques we have taught you. Each exchange takes about 30 minutes from start to finish. The timing of the exchanges can be flexible to your needs, but you must spread them out regularly through the day.

Some positive aspects of Peritoneal Dialysis

- This type of dialysis allows you freedom from hospital to carry out your treatment at home, at work or on holiday. Once you are established on dialysis routine, hospital appointments are usually every 1-2 months
- If you are waiting on a live donor transplant, but need dialysis for a short time prior to getting transplanted, PD is a good bridging treatment
- Most patients have fewer restrictions on their diet and fluid intake (compared to haemodialysis)
- Peritoneal dialysis allows freedom to travel – as it can take place outwith the home

Some potential negative aspects of Peritoneal Dialysis

- Potential risk of infection
- Peritoneal Dialysis (PD) is a time-limited treatment and we usually recommend that patients do not stay on PD for longer for 5 years due to the effect of PD fluids on the peritoneal membrane.
- You will need storage space at home to store fluid and disposables

Haemodialysis

Haemodialysis is the name of the treatment where blood is cleaned using a dialysis (kidney) machine. This treatment involves removing some blood from your circulation and pumping it through a man made membrane (often referred to as a dialyser or artificial kidney) that filters waste products out. The blood is then returned to your bloodstream. At any one time there is only a small amount of blood outside of your body. To allow enough waste products to be removed this treatment lasts 4-5 hours and is carried out three times every week. Haemodialysis can either be done at home or in a hospital Regular Dialysis Unit

Before you can start haemodialysis you need a form of access into the bloodstream. Where possible this involves a small operation to join two blood vessels (an artery and a vein). This is called a fistula and is usually made in the arm. Where possible this is made a few months before we expect you to need dialysis. This operation can be done as a day surgery procedure or may involve admission to hospital.

After the fistula operation, the fistula may not be ready to use for 6 weeks. This allows the fistula to mature. After the fistula is ready to use and when it is necessary to start dialysis, we can insert two needles at the start of each dialysis session – one needle to take your blood out and round the circuit and a

second needle to return the blood to your circulation.

At the end of each dialysis session we remove the needles, dispose of them and place a plaster on the spot where the needle was.

If your veins are too small or blocked, we may not be able to make a fistula in your arm and the surgeon may decide to put a graft in instead. A graft is a long piece of plastic like tubing that joins the artery and vein together. It does not need time to mature and often can be used straight away. We use a graft in the same way as a fistula, by inserting two needles into it at the start of dialysis and removing them at the end.

It may not always be possible to start dialysis with a fistula or graft. If a fistula has not been made or if it is not yet ready to use, you may need to start haemodialysis with a temporary type of access. This type of access usually involves the insertion of a tunneled plastic catheter into one of the body's large veins through the chest wall. This is usually done under local anaesthetic and is often referred to as a "permcath". This temporary access can be used straight away until a fistula is ready. If it is not possible to make a fistula, the permcath can be used as a long term type of access. Whenever possible it is better to use a fistula because there is less risk of infection.

Home Haemodialysis

This method of dialysis takes place in your home and you usually need someone to help.

You do not need to have any previous experience in healthcare as we will provide full training and support. You will learn to set up and operate a dialysis machine and to insert needles into your fistula. This involves a training programme which lasts 2-3 months and the community dialysis nurses at the New Stobhill Hospital carry this out. With this type of dialysis you do not need to travel to the regular dialysis unit and the timing of

dialysis sessions can be scheduled at a time that suits you. On this kind of treatment, your helper needs to be in attendance while you are on dialysis.

Some positive aspects of Home Haemodialysis

- Treatment sessions 3-6 times a week can be at times suitable to you and your helper
- Not having to travel to a Dialysis Unit
- More flexible – e.g. can do short frequent sessions
- Being in control of and taking responsibility for your treatment

Some potentially negative aspects of Home Haemodialysis

- You need someone to help you
- You need a dedicated space at home for dialysis machine and supplies i.e. a room or portakabin (which can be sited by the community dialysis team)
- Less flexible than CAPD and APD if you are planning to travel or go on holiday
- Restrictions on diet and fluid are likely

Hospital Based Dialysis

Not every patient will be suitable for a home therapy and in such cases patients may choose hospital haemodialysis.

This method of treatment involves travelling to one of the renal dialysis units (RDU) 3 times every week at a time appointed by the dialysis unit. Dialysis sessions are available in the morning and afternoon. Some units may have overnight or twilight dialysis. Nurses in the RDU will carry out and monitor your treatment. There will be time spent travelling to the unit and home again which adds time to the treatment.

Some positive aspects of Hospital Haemodialysis

- The treatment is 3 times a week
- Allows social contact with other dialysis patients
- Security of having trained staff in attendance during treatment
- No need to store supplies at home

Some potentially negative aspects of Hospital Haemodialysis

- Fixed schedule of dialysis sessions at times set by the dialysis unit – each treatment lasts 4-5 hours
- Travelling to and from dialysis unit involved and this time can be lengthy if using hospital transport
- Less flexible than CAPD and APD if you are planning to travel or go on holiday
- Levels of waste products and water build up between treatments
- Restrictions on diet and fluid are likely
- Potential problems with access including loss of function in fistula and infection risk of septicaemia associated with central venous catheters.

Choosing not to have dialysis

Supportive Care

Some people may decide after discussing all the facts that starting any form of dialysis would not be in their best interests and would not improve the quality of their life. In some circumstances, choosing not to have dialysis is a reasonable decision – for example when there are very severe and significant other medical problems.

If you are unsure if you would want dialysis in the future you should discuss your feelings with the Renal Team. You should

know that deciding not to have dialysis will not affect your care at the Renal Clinic. We will continue to treat your kidney disease and symptoms.

Most patients who choose not to have dialysis have other diseases and many people will die from a cause other than kidney failure before dialysis would have been necessary.

Some people may think that they would not wish dialysis but change their mind when the time comes. You should know that you can change your mind about having or not having dialysis at any time. In these circumstances, it may not have been possible to plan all of the preparation which is carried out in advance of starting dialysis treatment.

Choosing the best treatment option for you

Choosing the best treatment option for you can be a very difficult decision to make and The Renal Team will support you in making these decisions. For some people, transplantation or the type of dialysis they can choose is limited because some medical or surgical condition may make transplantation, haemodialysis or peritoneal dialysis technically difficult.

For the majority of people both methods of dialysis are possible and you (and those closest to you) need to decide which type of treatment will best suit you. It is important for you to have as much information as possible to help you make the best decision.

Some patients choose not to have any type of dialysis treatment (in the knowledge that not having dialysis when it is required will result in death) – this is discussed on page 15.

Additional Information

The information in this booklet and other reading or internet material will help.

We can arrange for you to visit the Peritoneal Dialysis clinic or one of the Renal Dialysis Units. Here you can speak to patients who are on these treatments and to the specialist nurses. This will also allow you to ask questions about what you have seen and read.

Things to think about

When you are thinking about different types of treatment, it can be useful to ask yourself these questions:

- Is living donation transplantation something that is a possibility for me and if it is, what do I need to do to start this process?
- Would a home based dialysis treatment be possible, and something that I would be interested in doing?

It is important that you have information about different types of treatment in advance so that the renal team can try to make sure that all the necessary preparations are in place before your need to start Kidney Replacement Therapy (KRT).

Examples of some of the preparation that should be done in advance include:

- Checking all patients who are likely to need KRT in the future for blood viruses such as Hepatitis B, Hepatitis C and HIV. We recommend that all patients who are hepatitis B negative are immunised against this virus before starting KRT.
- If living donation transplantation is an option, it may be possible for this to happen before you need dialysis. This process can take several months to complete.

- If dialysis is your preferred treatment choice, you will need to have an “access” created.

Further Reading

- Kidney Dialysis and Transplants by Dr. Andy Stein and Janet Wild (Class Publishing 2002)
- Kidney Failure Explained (2nd Edition) by Dr. Andy Stein and Janet Wild (Class Publishing 2002)

Useful Websites:

- **Kidney care UK.** For advice on benefits and financial support, counselling and access to various medpatient information booklets.
Website: 🌐 <https://www.kidneycareuk.org>
Helpline: ☎ **01420 541 424**
- **National Kidney Federation.** Information for patients.
Website: 🌐 www.kidney.org.uk
Helpline: ☎ **0845 601 0209** (9.00am to 5.00pm)
- **The Scottish Renal Registry** is a national database with information on kidney disease.
Website: 🌐 www.show.scot.nhs.uk/srr
- **The Kidney Patient Guide** is for kidney patients and those who care for them.
Website: 🌐 www.kidneypatientguide.org.uk
- **Patient Review** - patients can access blood results and medical information using a secure and confidential system called “Patient Knows Best”
Website: 🌐 <https://patientsknowbest.com/>
- **Edinburgh Royal Infirmary’s renal unit** site is a good source of information about kidney diseases for patients
Website: 🌐 www.edren.org

- **At home with dialysis'**, a video guide for patients new to Peritoneal Dialysis (PD), created by Baxter Renal Care.
🌐 https://www.baxterglobal.com/at_home_dialysis
- For more information on kidney donation, please visit
🌐 <https://www.organdonation.scot>.
- Potential donors may register their interest by phoning the Living donor transplant coordinators on
☎ **0141 451 6200** or by e-mail:
@ ggc.renallivedonorteam@nhs.scot
- Diet and CKD video link:
🌐 <https://youtu.be/wtw5tay0K4>
- If you google NHSGGC Diet and CKD it comes up or scan the QR code.



Benefits Advice

- The long Term Conditions and MacMillan Money Advice Service offers free confidential advice to people who live with long term health conditions. They offer specialist advice and information on benefits, tax credits, grants and loans.
- Phone: ☎ **0141 287 5901**
- e-mail: @ LTCandMacMillanService@glasgow.gov.uk

If you wish to discuss anything contained in this booklet or any other aspect of your kidney disease, you can contact:

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