NHS
Imperial College Healthcare
NHS Trust

Renal department

Treatment options for advanced chronic kidney disease

Information for patients, relatives and carers

Introduction

This booklet is designed to help you understand more about treatment options and the information available when your kidney disease falls to stage 5 and you can no longer continue to be well with medications alone.

What are the treatment options?

Your renal team (consultant, doctor and advanced kidney care nurse specialist) will explain which treatments may suit you based on your individual health needs and personal circumstances. The aim is to help guide you to make an informed decision about your care. We will invite you to information seminars covering all types of treatment. It is advisable to look at your options in plenty of time to understand and discuss your options with your family, friends or carers.

The following treatments are available:

- **transplantation —** it is possible in many cases to have a kidney transplant from a living donor or a deceased donor. We know that living donation gives the best outcome and is better if done before you need any dialysis (known as pre-emptive transplantation).

- **dialysis —** if you are not able to have a transplant due to medical or personal reasons or are waiting for a transplant, the renal team will discuss your preferred dialysis choice with you. Dialysis treatment can be done either at home (known as home therapy) or in hospital by one of the following methods:

    - **peritoneal dialysis (PD):** this is a home therapy (please see page 4)

    - **haemodialysis (HD):** this is primarily a hospital-based treatment but can also be a home therapy (please see page 6)

Supportive care (also known as conservative care): this is an option for some people where transplantation is not possible and dialysis may not bring significant benefits. We will explain this in more detail and help you decide if this is right for you.

Can I have a kidney transplant?

A kidney transplant is the best treatment for replacing and restoring normal kidney function. An in-depth assessment will take place to determine if you are fit enough to undergo the transplant operation. Sometimes you may need additional treatments before the operation to improve your fitness. We will provide you with information to help you understand fully what is involved in having a transplant and its lifelong aftercare.

There are several different types/ways to receive a transplant:

- **Living donation** is where someone is willing to donate one of their kidneys to you. A donor can be someone related, such as a spouse, family member or friend, or someone unrelated. Living donation is a planned operation so, with this option, it is possible to plan a transplant before you reach the need for dialysis (pre-emptive transplant). This type of transplantation has the best outcomes.

  Any living donor will need to be assessed as fit and healthy and suitable to donate. They will also need to be a suitable match with regard to blood group and tissue typing. If a donor is not a match, you may still be considered for a living transplant through a UK living kidney sharing scheme.

- **UK living kidney sharing scheme** is a system where people who wish to donate but are not a match with their family member / friend can be entered into a pool with other people who are also not a match (known as pairs). The pairs are compared and if there are any matching pairs within the pool, each donor can donate to the other pair’s family / friend.

  If you know someone who is interested in being a kidney donor for you, please discuss this with your renal team who can provide specific information about living donation and put your donor in contact with the living donor transplant coordinators.

- **Deceased donation** is where a kidney is donated by a person who has died. To receive a deceased donor transplant, you must be activated on the national kidney transplant deceased donor waiting list. Once you are active, you could be called to receive one of these at any time. People may wait many years on this list for a transplant.

- **Altruistic donation** is where people from the general public volunteer to donate a kidney to an unknown person who is on the deceased donor list or in a sharing scheme.

- **Simultaneous pancreas and kidney (SPK)** transplant is suitable for some people with diabetes since it provides a new kidney and pancreas. If you have diabetes, your renal team will discuss with you whether a SPK transplant would be an option for you.

There is a great deal more transplant information available through seminars, leaflets and recommended websites and by discussing these options with your renal team.

What is dialysis and when will I need it?

Dialysis is the name given to the artificial means of filtering the blood in your body because your kidneys can no longer filter the blood sufficiently. There are two types of dialysis: haemodialysis and peritoneal dialysis. Both types of treatments can be self-managed at home and are described on pages 4-7.

We will encourage you to start learning about which type of dialysis you would prefer based on your individual health needs and personal circumstances. The timing will depend on your condition and the rate of decline of your kidney function. This usually starts during stage 4 (eGFR 15 – 29 ml/min). You will usually need to start dialysis when the kidney function falls below eGFR 10ml/min. Some people will have many symptoms and need to start earlier (lethargy, tiredness, breathlessness, itching). The renal team will advise you when dialysis is needed.

Which form of dialysis is right for me?

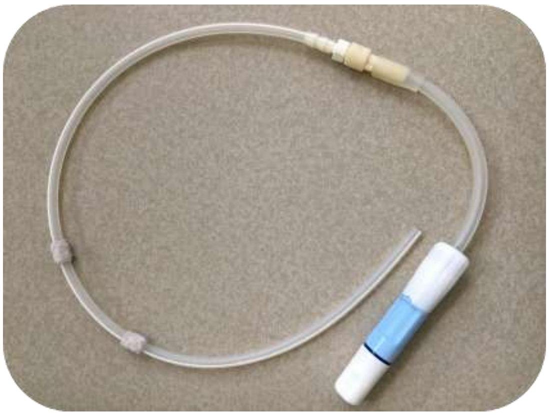
Sometimes there are medical reasons why one type of dialysis might not be suitable for you. For most people though, you are free to choose the type of dialysis that best suits your lifestyle.

The following are some questions to consider when thinking about which treatment would be most suitable:

- where does the dialysis happen?
- how often does the dialysis take place?
- how much travel time will be needed?
- how will I feel after dialysis?
- can I continue to work?
- how are holidays arranged?
- what family or friend support do I have?
- how strict are the fluid and diet restrictions?
- what storage space do I need at home?

What is peritoneal dialysis (PD)?

Peritoneal dialysis is a home therapy that you learn to carry out yourself. Your suitability for PD will be decided by a physical and social assessment. During your assessment, we will determine whether you could manage the treatment independently or whether you will need help. This could be a family member helping you or a healthcare assistant.
For those able to carry it out themselves, it is not difficult to learn and full training is provided. It usually takes 3-5 days to learn and become confident. It means that you do not have to make frequent trips to hospital. It is flexible and, if self-managed, can allow more freedom to go on holiday in the UK and abroad.



How do I prepare for peritoneal dialysis?

Peritoneal dialysis uses the space inside your abdomen called the peritoneal cavity. The cavity is lined with a membrane which acts as a filter. The peritoneal cavity is filled with dialysis fluid (1.5 – 2.0 litres) via a small plastic catheter. The waste products are drawn through the peritoneal membrane into the fluid in the cavity. The fluid is then drained out and takes excess waste and fluid from your body. New fluid is then replaced to continue the filtering.

Before starting the treatment, you will need the small plastic catheter inserted into your peritoneum. This can be done using a local or general anaesthetic.

After insertion, the catheter is usually left to ‘rest’ for at least two weeks. During this ‘resting’ period, you will have appointments in the home therapies unit at Hammersmith Hospital to check your wound dressing and your blood results.

We will plan your dialysis training with you. After you have been trained, we will arrange for you to be set up at home with all the equipment and supplies that you need for your treatment.

How often is peritoneal dialysis performed?

Peritoneal dialysis can be done either manually during the day or via a machine overnight:

Automated Peritoneal Dialysis (APD) — this involves being attached to a dialysis machine at night for usually eight to nine hours for five or six nights per week. Your individual regime will be assessed by the home therapies nurses.

The machine takes approximately 20 minutes to set up and can be done in advance during the day. The machine is pre-programmed to exchange the dialysis fluid several times while you are asleep. It is not noisy but you might notice a quiet hum when it is working. The machine can be stopped temporarily if you need to go to the bathroom. In the morning it takes approximately 10 minutes to disconnect yourself and clear away all the disposable equipment. You then have your day free.

Continuous ambulatory peritoneal dialysis (CAPD) — this can be performed during the day and the frequency can vary from two, three or four times per day, usually five to six days per week. Your individual regime will be assessed by the home therapies nurses.

Each exchange takes about 30-45 minutes to drain the fluid from your abdomen and replace it with new fluid. The exchange of dialysis fluid can be done in any clean area so you are not restricted to being at home. Once completed you are free to carry on with your usual daily activities.

How much storage space do I need to perform peritoneal dialysis at home?

You will need to have enough storage space for a delivery of two to four-weekly stocks of dialysis fluid and other supplies. Your boxes of dialysis fluid can be stored anywhere where it is dry and away from direct sunlight.

If you are interested in peritoneal dialysis, we will invite you to one of our ‘Know your dialysis options’ seminars where we will demonstrate what is involved. For further information, please contact your advanced kidney care nurse specialist.

What is haemodialysis?

A small amount of blood is taken out of your body and circulated around a dialysis machine for a prescribed number of hours. This is usually done via an arterio-venous fistula (AVF) or, in some cases, a plastic catheter. The dialysis machine cleans your blood by passing it through a filter (dialyser) and then returning it to you continuously. You will be attached to the machine for three to six hours depending on your prescription, usually three times per week. Timing may vary in some cases according to need.

Haemodialysis can take place in a hospital setting either independently (shared care) or with nursing assistance. Alternatively, it can be carried out independently at home.

Haemodialysis as a home therapy

Dialysis at home has advantages as it saves travelling to hospital three times each week to fit in with the hospital schedule.

You can train and carry out your treatment safely at home. We will support you in learning how to perform your own treatment. Once you have trained and set up at home, you can organise your dialysis sessions around your work, family and social life.

You will have a weekly prescription such as 12 to 15 hours per week, however, you can choose your timings. More frequent dialysis can have advantages of improved wellbeing, often fewer medications are required and fewer dietary and fluid restrictions. You will also have greater independence and freedom, with support and information just a phone call away.

Haemodialysis in hospital

Dialysis in hospital takes place in a local dialysis centre. The nurses may perform your dialysis treatment or you may train to be independent (shared care). If your aim is to ultimately dialyse at home you will be offered shared care in a local unit first to allow you to learn and build your confidence before you go home.

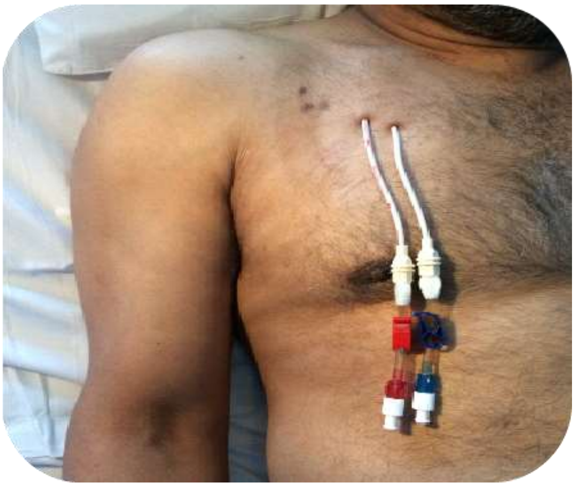
The aim will be to allocate you to a dialysis centre close to your home or work. In order to do this you will need to be fit enough to dialyse in a local dialysis centre and a space will need to be available. When you first start your dialysis you may need to initially dialyse at Hammersmith Hospital's Auchi unit. Once you are fit and a space becomes available, we will transfer to your chosen unit. Initially this may not be the most convenient day, time or location for you but you can join a waiting list for your preferred day, time or location.

How do I prepare for haemodialysis?

To perform haemodialysis you will need a small operation to create access to your blood system (vascular access) so that your blood can be taken from your body and returned during the dialysis session. There are two types of access and you will be assessed by the vascular access team as to what type of access is suitable.

Arterio-venous fistula (AVF) access — this is the best form of long-term access for haemodialysis. A small operation takes place to join an artery to a vein in your arm to create a 'super vein'. This is usually under local anaesthetic and as a day case. We will plan to create a fistula three to six months before you need to start dialysis. Once the AVF vein has sufficiently enlarged, usually about two months after the procedure, it is then ready for when you need to start dialysis.

Dialysis catheter — a dialysis catheter involves two plastic tubes being inserted into one of your major blood vessels near your collar bone, usually under local anaesthetic, immediately before you start your dialysis. The catheter shown in the picture on the right is known as a Tesio® catheter.
This can be a temporary option if you are waiting for your AVF to mature, or more permanent if your veins are assessed as unsuitable for a fistula formation.



What is vein preservation?

It is really important to protect the veins in your arm for any future fistula formation. Veins can be damaged each time you have a blood test. We would advise anyone with advancing kidney disease to avoid blood tests from inside your elbow. Ask to have bloods taken from the back of your hand instead. If this is not possible then you should use only the arm you usually write with for your blood tests or alternate arms.

What happens if I do not have dialysis and choose supportive care?

Having dialysis can be challenging. For some people with multiple medical conditions, it might not improve survival or quality of life. Some people may therefore choose not to start dialysis.

The aim of supportive care is to maintain a good quality of life for as long as possible by controlling symptoms with medications, diet and fluid restrictions. In this case it will be important to plan for the future and think about where you want to be cared for when you become less well and near the end of your life. This is called an advanced care plan and may involve your GP, district nurses and the community palliative care team. We will continue to support your care and offer clinic appointments as long as you are able to attend. We will continue to provide telephone advice to the GP and palliative care team as requested if you can no longer attend.

Both our experience and research shows that many patients who choose not to have dialysis may still live for many months or a year, sometimes more. Sometimes saying no to dialysis gives a better quality of life, with less time spent in hospital.

If you are thinking about choosing supportive care, it is important to discuss your wishes with your family and friends as well and we can support you with this. We have experienced counsellors who are also here to help you explore your decision in more depth if you want to.

Renal counselling and social support

Making decisions about your future treatment can, understandably, have an impact on your work and home life. We have a counselling and social support team who will be able to support you when you are considering your options for starting treatment, during transition when treatment starts and throughout your treatment.

The counselling and social support team consists of two qualified renal counsellors and a qualified renal social support worker. Our team understands the impact that starting treatment can have both emotionally, psychologically and socially and are here to provide support.

Renal counselling and social support team

Lead renal counsellor: 020 3313 6620

Renal counsellor: 020 3313 5341

Renal social support worker

Renal social support worker: 020 3313 6619

Further information

For further information on treatment options, contact your nurse

Advanced kidney care nurse specialist team:

Ashford	**020 3313 0984**
Charing Cross	**020 3313 0984**
Central Middlesex	**020 8453 2693**
Chelsea & Westminster	**020 3311 1972**
Hammersmith	**020 3313 5247**
Northwick Park	**020 8869 5027**
St Mary's	**020 3312 1267**
Watford	**01923 217 240**
West Middlesex	**020 3313 2598**

Haemodialysis dialysis units:

Auchi unit, Hammersmith	**020 3313 6627**
Central Middlesex	**020 8453 2017**
Charing Cross	**020 8846 1752**
Ealing	**020 8967 5737**
Hayes	**020 3313 9800**
Northwick Park	**020 8869 3245**
St Charles	**020 8962 4810**
Watford	**01923 217 243**
West Middlesex	**020 8321 2543**

Live donor co-ordinators	**020 3313 8145 / 1926**
Recipient co-ordinator	**020 3313 5240**

Other useful contacts

Hammersmith Hospital switchboard: **020 3313 1000**
Renal rapid assessment unit: **020 3313 6603 / 6604**
Pam Sassoa planned investigation unit (PIU): **020 3313 6683**

Useful websites

Imperial College Healthcare renal and transplant unit	www.imperial.nhs.uk/renal
West London Kidney Patients' Association	www.westlondonkpa.org
Kidney Care UK	www.kidneycareuk.org
Kidney Research UK	www.kidneyresearchuk.org
Polycystic Kidney Disease	www.pkdcharity.org.uk
National Kidney Federation	www.kidney.org.uk
Edinburgh Renal Unit	www.edren.org/ren
Guys & St Thomas's & Kings	www.mykidney.org
Beaumont Hospital	www.beaumont.ie/kidneycentre-home

- **British Association for Counselling and Psychotherapy** for additional information about counselling and psychotherapy and how to access a therapist privately: www.bacp.co.uk

- **Samaritans** To talk to someone right now call 08457 90 90 90 www.samaritans.org

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How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

Renal department
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