>>> INFORMATION FOR PATIENTS

UNDERSTANDING TREATMENT OPTIONS FOR KIDNEY DISEASE

Vantive

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At Home

Hospital

WHAT IS HAPPENING TO ME?

When you hear you have chronic kidney disease, it can be a shock: dialysis or a kidney transplant can affect many aspects of your life and have a big impact on the way you live.

Understanding what is happening may help you and your family to organise the future in the best possible way and help you to adapt to the new situation.

This booklet has been designed for people who have kidney failure, to provide information about the treatment options that are available.

However, this booklet cannot replace the discussions that you will have with the people in your hospital such as the specialist doctors, nurses and dieticians you can take it home and read it at your own pace, using the information to add to what you've been told.

The information and education provided by your renal team is designed to answer all the questions you might have, to support you when making a decision on which treatment is the best for you and to help you fit the treatment in your daily life.

You are not alone.

There are many people in the renal team who can help.

THE KIDNEYS: HOW DO THEY WORK?

The kidneys play an important role in your health.

Most people are born with 2 kidneys – one on each side of the backbone just below the ribcage. Shaped like a kidney bean, each kidney is about the size of a small fist (12 cm) and weighs about 150 grams.

Normal healthy kidneys;

- Clean waste products from your blood
- Remove excess fluid
- Help to control your blood pressure
- Help to make red blood cells
- Produce vitamin D to keep bones healthy and strong

WHAT HAPPENS WHEN YOU HAVE CHRONIC KIDNEY DISEASE (CKD)?

Having kidney disease means that your kidneys gradually lose their functions. So...

- They don't filter your blood well
- They don't remove the excess fluid well
- You may have problems with your blood pressure
- You may suffer from anaemia and bone disease

The most common causes of chronic kidney disease are:

- Diabetes
- High blood pressure
- Damage to the part of the kidney that filters your blood
- Polycystic kidneys
- Long term or frequent infections of the kidney

What are the symptoms of kidney disease?

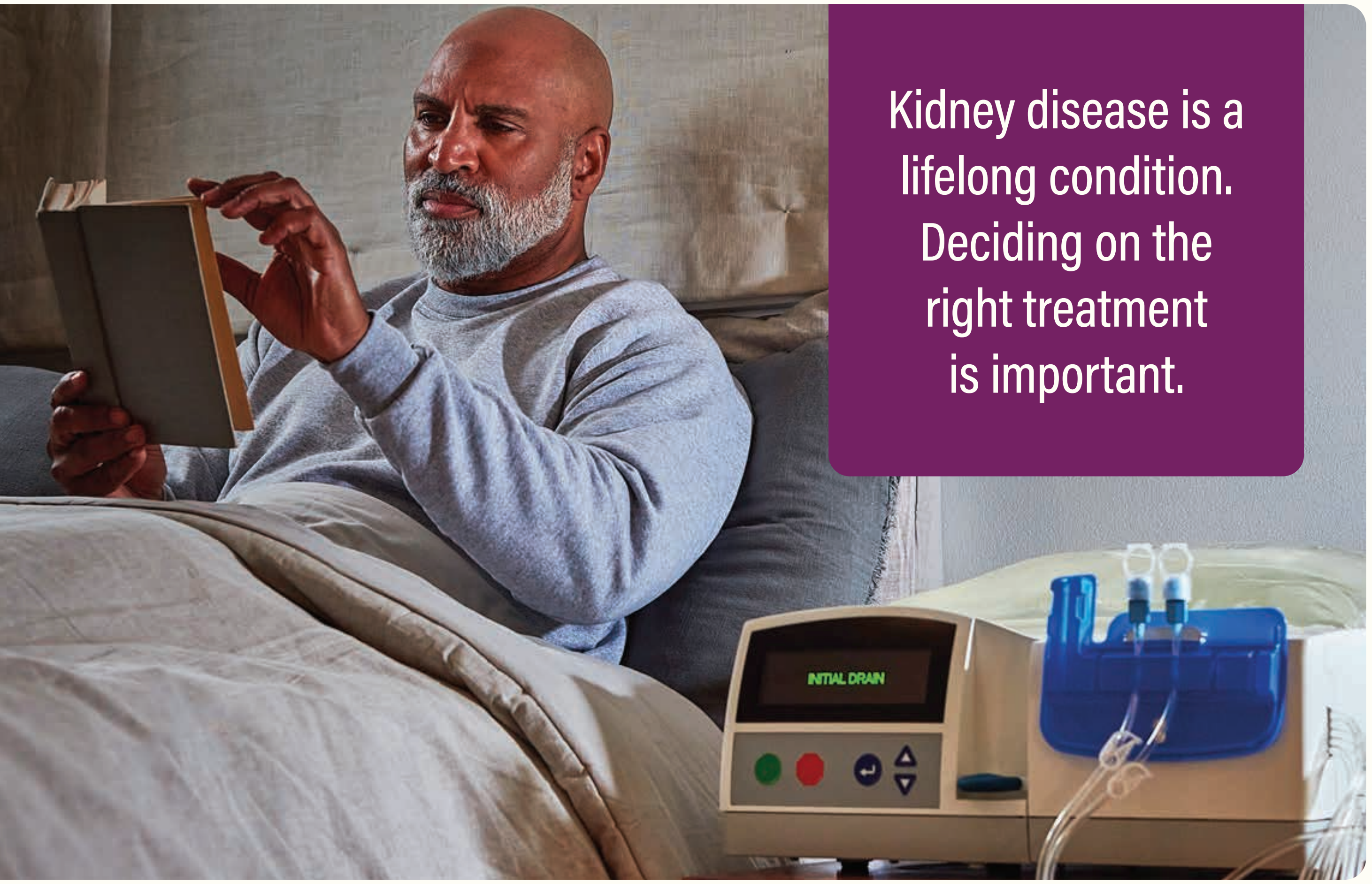
The symptoms of kidney disease can vary from person to person some people with kidney disease may not feel ill, or they may not notice their symptoms.

Often, some people do not feel ill until their kidneys are no longer removing waste. This is why kidney disease is sometimes called a 'silent' disease.

Symptoms usually include:

- Feeling tired and/or weak
- Swelling of the hands and feet
- Shortness of breath
- Appetite loss, a bad taste in the mouth, vomiting, nausea, weight loss
- Difficulty sleeping, itching, muscle cramps, darkening of the skin

WHAT ARE THE TREATMENT OPTIONS FOR KIDNEY DISEASE?



Kidney disease is a lifelong condition. Deciding on the right treatment is important.

Remember that your needs may change so the treatment that you start on may not always be the best one forever. It's therefore a good idea to think about the future and regularly talk to your renal team about your options.

> Think about how much independence you want with your treatment; whether you have it at home or in hospital.

> Research tells us that people who are involved in their care and who do more for themselves can have a better quality of life and have fewer symptoms.[1]

> Discuss with your renal team what is right for you now and in the future remember that you can always discuss the options again and change your treatment if it's appropriate.

The 3 Treatment Options

Kidney Dialysis

Dialysis is a treatment that does some of the work of the kidneys when they aren't working properly.

> You can have dialysis at home: Peritoneal Dialysis or Haemodialysis. Alternatively you can choose to have Haemodialysis in a hospital setting.

If you would like to do your dialysis at home, there is lots of support given to you. You are not on your own. The whole team will make sure you can be treated safely at home and help will only be a phone call away.

Some home dialysis machines are connected to the internet so the renal team can keep an eye on your treatment. This can be very reassuring for some patients. If you find it difficult to manage alone, Healthcare Assistants are available to do some of the dialysis, until you become more confident.

Kidney Transplant

This treatment is when a healthy kidney from one person (donor) is given to a patient with kidney failure (recipient).

A transplant is performed by a surgeon during a transplant operation.

Conservative Medical Treatment

Conservative treatment helps to control some of the symptoms of chronic kidney disease by using medicine and injections like diuretics (water tablets) and Erythropoietin (EPO) which helps treat anaemia.

For more information about conservative treatment speak to your renal team.

IF YOU DECIDE TO HAVE DIALYSIS, WHAT ARE YOUR OPTIONS?

Remember, it is possible to change treatments if the one you are on doesn't suit you, so discuss this regularly with your renal team.

At Home

Your renal team will provide you with the necessary training and support to ensure you can treat yourself safely at home.

> You will be able to do the treatment at times to suit your lifestyle e.g. Continuing to work or attending daytime activities.

> You will come to the hospital every 1-2 months for a visit with the renal team.

> A nurse may visit you at home, but will be available to speak to you whenever you need advice.

> Patient support groups are available, please ask your renal nurse for more information.

> Some home dialysis machines are connected to the internet so that the renal team can keep an eye on your treatment, giving you peace of mind.

In Hospital

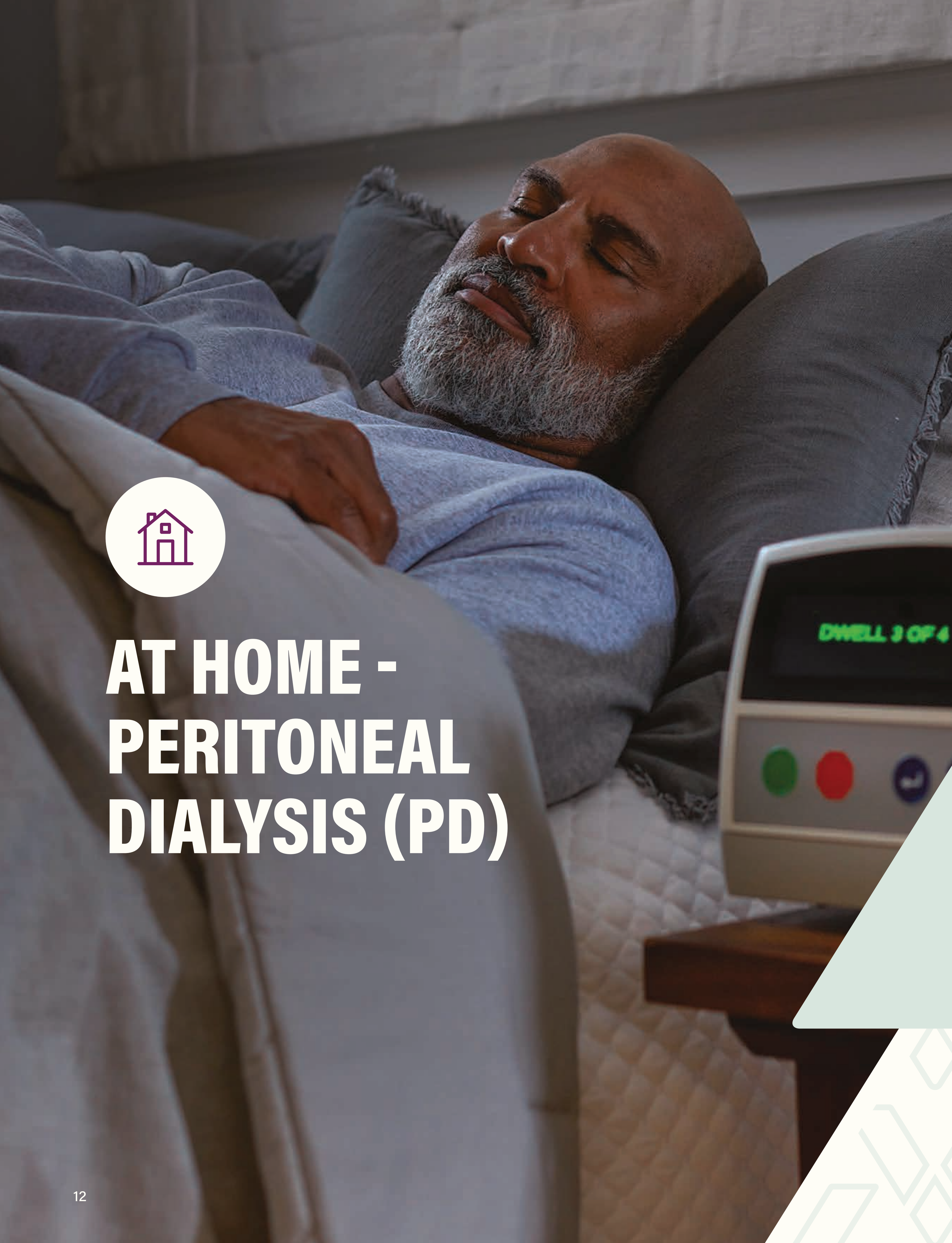
In Center Haemodialysis occurs in the hospital, the renal team will be present during the treatment.

> The dialysis treatment times are fixed and normally last for 4 hours a day, 3 times a week (conventional dialysis).

> You will meet other patients at the renal unit.

> You need to travel to and from the hospital 3 times a week.

> Even if you choose a hospital-based dialysis, you can still take part in your treatment. Ask about self-care or minimal care.



AT HOME - PERITONEAL DIALYSIS (PD)

Choosing PD as the first treatment option can have some benefits;

- PD can help preserve remaining kidney function[2] for longer this is because it is a continuous therapy, meaning that there are no gaps in treatment.
- You do not need to have blood taken out of your body to have PD this means that your veins can be remain healthy for haemodialysis if you need to have that in the future.
- For people who are waiting for a kidney transplant, PD can help improve the chances of a successful kidney transplant.[3]

AT HOME – PERITONEAL DIALYSIS (PD)


PD catheter

How does it work?

To have peritoneal dialysis you need to have a **PD catheter** (a soft plastic tube). This tube remains inserted in your tummy and is used to get the PD dialysis solution in and out of the peritoneal cavity – the space inside your body where the dialysis takes place. The PD catheter is placed during a simple minor operation under a local or a general anaesthetic at the hospital. The catheter and the exit site (the place where the catheter comes outside), will need daily care.

- PD dialysis solution stays in the peritoneal cavity so that excess fluid and toxins can be removed. The fluid is changed regularly – this is called an exchange. Dialysis is continuous meaning that fluid and toxins are being removed whenever the dialysis solution is inside the body.
- You and often a helper/partner/carer will be given expert training by the nurses to make sure that you can treat yourself safely at home. The length of the training can vary; on average it takes a week but can be longer or shorter, depending on your needs.
- Once you are at home, the supplies will be delivered to your home every month. You will need space at home to store supplies.
- You will be reviewed by your renal team regularly. There is also always someone available on the phone. You can contact the renal team by phone, if you have questions or problems - the line is open 24 hours a day, 7 days a week.
- Some PD machines connect to the internet so that the nurses and doctors can keep an eye on your treatment every day.
- If you need assistance to perform the therapy, a Renal technician can come and help you.
- If you need to travel for work or holiday, you can take your PD machine with you. Your dialysis supplies can be delivered almost anywhere in the world and dialysis can be done wherever there is a clean and convenient place. So going on holiday or visiting friends is easy.

HOW IS THE TREATMENT PERFORMED?

Continuous Ambulatory Peritoneal Dialysis (CAPD)

This is done using bags of dialysis fluid which are exchanged through the PD catheter manually, usually 1-4 times a day. Each exchange takes about 30-45 minutes.

Automated Peritoneal Dialysis (APD)

This is done using a machine to exchange the dialysis fluid through the PD catheter during the night while you are asleep.

Most people find PD easy and can learn to do it in a few days.

You can take as long as you like to learn, and it's a good idea if a family member or friend learns with you.

Some people need more help so a nurse or renal technician may be able to help with the dialysis in your home. This support can be temporary, for just a few weeks, or it can be for as long as you need it.

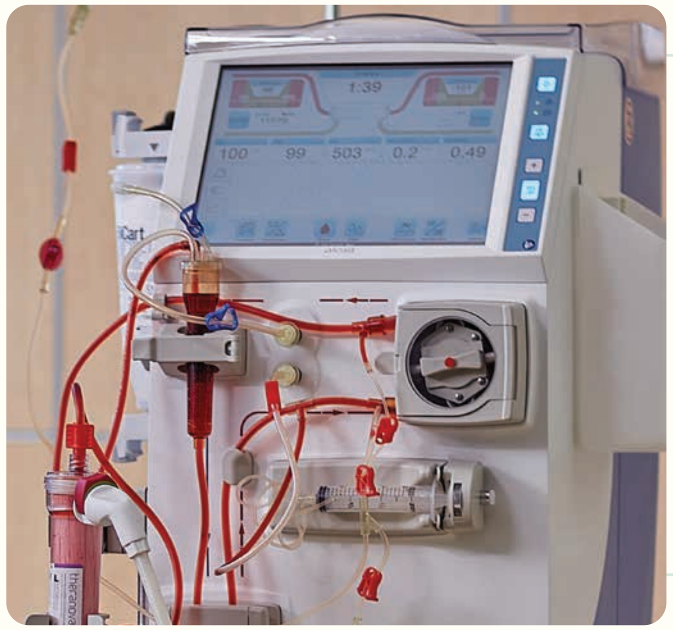
HOME HAEMODIALYSIS (HHD)

How does it work?

To have HHD you will need a specially-formed blood vessel (**fistula**) to be made. This is done during a minor operation where a vein and an artery (blood vessels) are joined together to make one big blood vessel.

- During HD, needles are put into the fistula to take blood out and return it to your body. During dialysis the blood passes through an artificial kidney, where the waste and water is taken out. This is the same for haemodialysis at home and haemodialysis in the hospital.
- If you do not have a fistula, a haemodialysis catheter (plastic tube) can be used to take the blood to and from the dialysis machine (see page 21).
- Recent research has shown that having more frequent HD or doing it for longer hours (overnight) has many benefits for patients already on dialysis.[4] More frequent dialysis is much easier if you can do it at home.
- People who have more dialysis usually take less medication for blood pressure and phosphate control compared to conventional haemodialysis.[5]
- If you choose to have HHD your renal unit will make sure everything is set up at home and you and/or your partner/carer are trained to do the dialysis safely.

HOME HAEMODIALYSIS (HHD)



For HHD you will need:

- A water and electricity supply
- Space for the machine so that you can do the treatment the HHD team will work with you to assess what needs to be done to make it possible
- Space to store the supplies

The supplies will be delivered to your home every month.

You may need assistance from a partner, community nurse, or another person who will need to be trained with you.

You will be regularly reviewed by your hospital team

This happens at least every 2 months. The nurses may also come and see you at home. If you have any questions or problems you can call the care team; they are available 24 hours a day, 7 days a week.

Some home dialysis machines are connected to the internet

This is so that the doctors and nurses can keep an eye on your treatment, giving you peace of mind.

How is the treatment performed?

Haemodialysis is performed in the same way at home and in hospital, however the main difference is that you can choose when you do your dialysis if you have it at home.

There are different treatment options

- **Short daily** – dialysis for 2 to 3 hours, 5 or 6 times a week.
- **Overnight** – dialysis for 6 to 8 hours, 5 or 6 times a week whilst you sleep this is also called nocturnal HHD.
- **Conventional HD** – dialysis 3 times a week for 3 to 5 hours.

The team at your renal unit will discuss these options with you. You can choose the days and the timings of the dialysis.

- During the dialysis sessions you can either sit in a chair or lie in bed next to your machine.
- You can watch TV, work on the computer, read, sleep, eat or be with your family. There is 24-hour support; your renal unit is only a phone call away!
- Travelling whilst on haemodialysis is possible; you will need to find a renal unit that offers holiday dialysis. **Ask the nurses at your hospital for more information.**

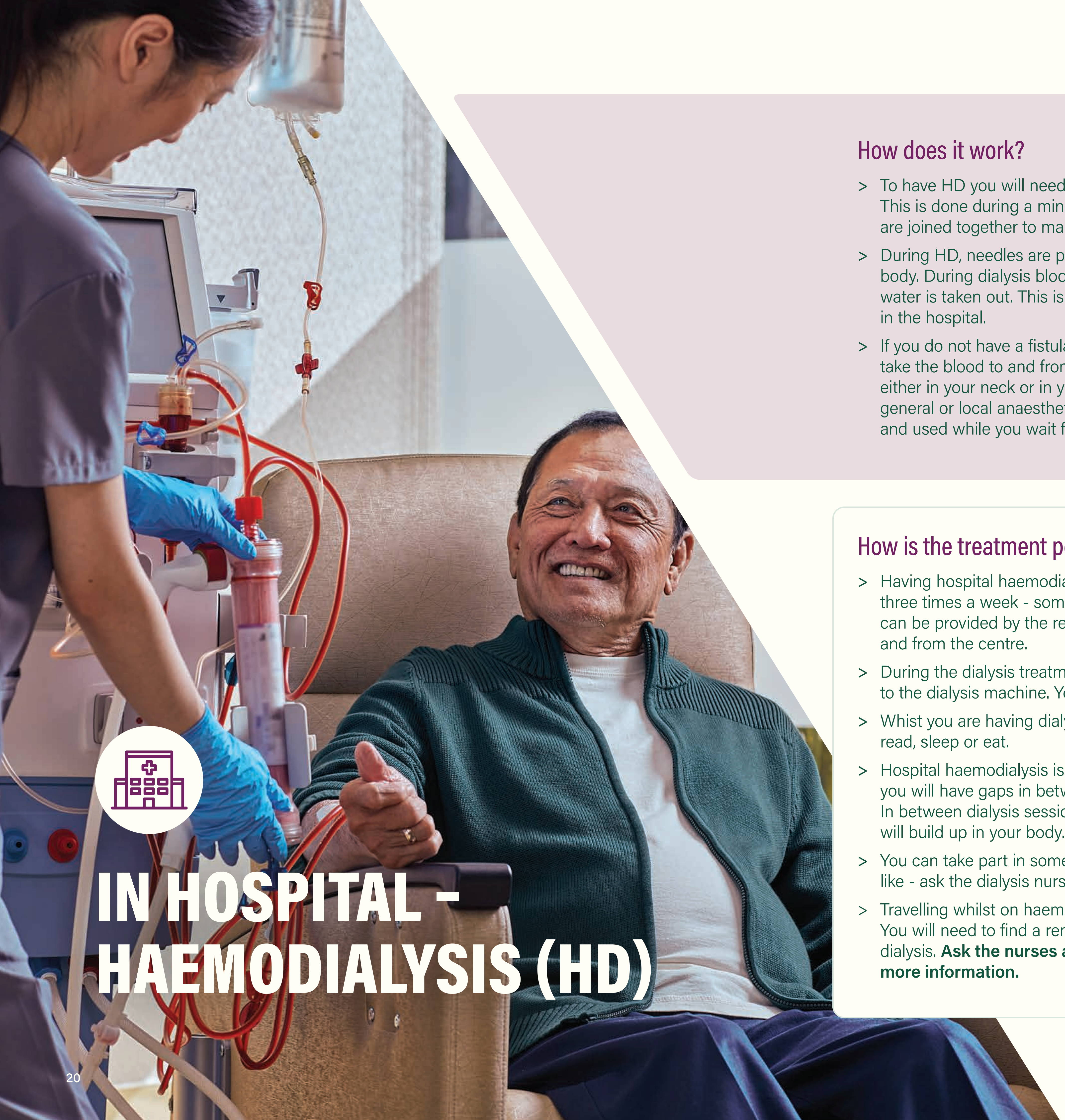
HHD Training

The training usually takes between 2 and 12 weeks, depending on the individual needs of each patient.

You will be taught how to;

- Set up the machine
- Put the needles in and connect to the machine
- Monitor your treatment
- Disconnect from the machine
- How to handle any problems.

Your renal unit will make sure you are ready and confident before you go home to do your dialysis.



IN HOSPITAL – HAEMODIALYSIS (HD)

How does it work?

- To have HD you will need a specially-formed blood vessel (fistula) to be created. This is done during a minor operation where a vein and an artery (blood vessels) are joined together to make one big blood vessel *(see page 17).*
- During HD, needles are put into the fistula to take blood out and return it to your body. During dialysis blood passes through an artificial kidney, where the waste and water is taken out. This is the same for haemodialysis at home and haemodialysis in the hospital.
- If you do not have a fistula, a haemodialysis catheter (plastic tube) can be used to take the blood to and from the dialysis machine. It is put into a large vein – usually either in your neck or in your groin. This is done in a short simple operation, under general or local anaesthetic. A haemodialysis catheter may only be temporary and used while you wait for your fistula to be formed or developed.

How is the treatment performed?

- Having hospital haemodialysis involves travelling to the dialysis centre three times a week - some units are open from 7am until 11pm. Transport can be provided by the renal unit, or you can make your own way to and from the centre.
- During the dialysis treatment you will sit in a chair or lie in a bed next to the dialysis machine. You will meet other patients at the renal unit.
- Whist you are having dialysis you can watch TV, work on the computer, read, sleep or eat.
- Hospital haemodialysis is an intermittent treatment, meaning you will have gaps in between treatment of one or two days. In between dialysis sessions the toxins and excess water will build up in your body.
- You can take part in some or all of your treatment if you like - ask the dialysis nurses about shared care dialysis.
- Travelling whilst on haemodialysis is possible. You will need to find a renal unit that offers holiday dialysis. **Ask the nurses at your hospital for more information.**

REVIEW OF THE DIALYSIS OPTIONS

Peritoneal Dialysis >>>

Benefits

- Choosing PD as your first dialysis option will help to preserve your remaining kidney function.
- Needles are not needed in PD. This helps you to preserve your veins for the future in case you need haemodialysis.
- For people who are waiting for a transplant, PD can improve the chances of a successful kidney transplant.
- PD is a continuous treatment which means that there are no great changes to the levels of toxins or fluid in your body.
- There is no need to travel to a dialysis centre for treatment.
- Privacy, flexibility and the comfort of being able to have dialysis at home.
- Treatment can be done at a convenient time based on your lifestyle.
- Dialysis supplies are portable and dialysis can be performed almost anywhere.
- Arrangements can be made so that you can travel or go on holiday with your dialysis supplies.

Points to consider

- A plastic tube – the PD catheter needs to be placed in your tummy.
- In CAPD exchanges must be done between 1-4 times per day, 5-7 days a week. Your Doctor will tell you exactly when to start.
- APD uses a machine in your bedroom and you will usually need to dialyse between 5-7 times a week whilst you sleep. Your Doctor will tell you exactly when to start.
- You need to be trained how to do the treatment.
- You may want to consider how dialysis at home will affect your family.
- You will need storage space in your home for supplies.
- There may be some changes to the amount of fluid you drink and your diet.

Home Haemodialysis >>>

Benefits

- Having haemodialysis at home means that you can have dialysis more often. Recent research has shown that having more frequent dialysis or longer hours (overnight) has many benefits for patients already on dialysis.[4]
- People who dialyse more, generally take less medication for blood pressure and phosphate control compared to conventional haemodialysis.
- There is no need to travel to a dialysis centre for treatment.
- Privacy, flexibility and the comfort of being able to have dialysis at home.
- Treatment can be done at a convenient time based on your lifestyle.
- Arrangements can be made for you to go on holiday, but you will need to find a dialysis unit near to your hotel, that can fit you in. You can discuss this with your renal team.

Points to consider

- You will need to have access to your blood stream through a fistula with needles.
- You (and usually a helper) need to be trained.
- You may want to consider how dialysis at home will affect your family.
- You will need space for the machine and storage space in your home for supplies.
- Minor modifications need to be made to electricity and plumbing for the machine and water treatment in your home to use equipment.
- There may be some changes to the amount of fluid you drink and your diet.

Hospital Haemodialysis

Benefits

- Nursing staff and healthcare assistants perform the treatment for you in the hospital.
- There is no need to store equipment or supplies at home.
- The treatment is intermittent – usually 3 times a week, so you have 4 days ‘off’ treatment per week.
- You can still be involved in your treatment and share responsibility for your dialysis.
- You will meet other people in a similar situation to yourself.
- Arrangements can be made for you to go on holiday, but you will need to find a dialysis unit near to your hotel, that can fit you in. You can discuss this with your renal team.

Points to consider

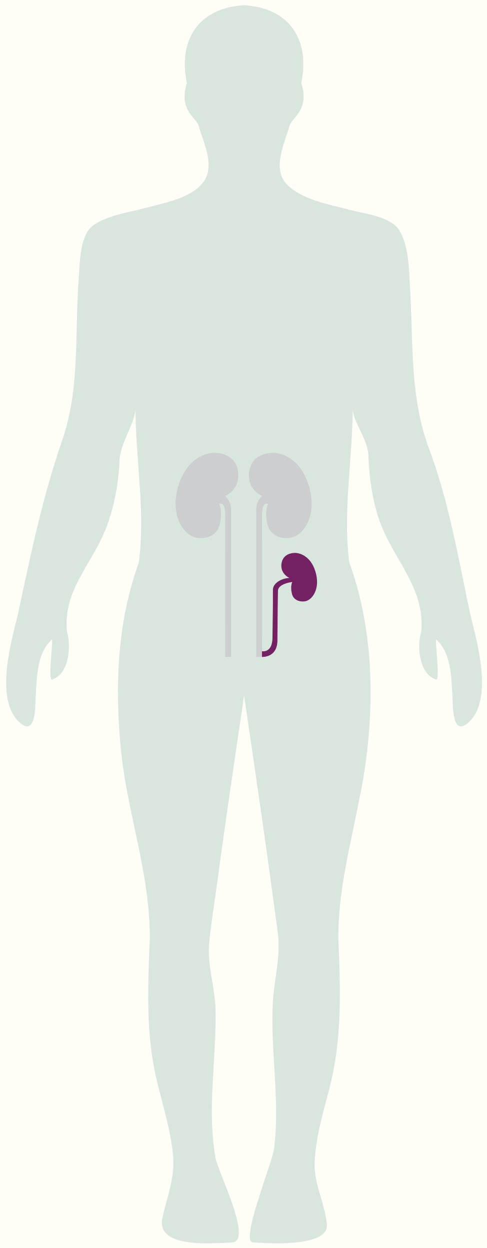
- You will need to have access to your blood stream through a fistula with needles or through a dialysis catheter.
- You will need to travel to the renal unit 3 times a week to have the dialysis, this can be during working hours, while some units may offer ‘twilight’ or night service.
- You may not be able to continue to work due to the timing of your dialysis, however it may be possible to organise sessions to fit in with work.
- If your dialysis is done only three times a week, it is likely that there will be restrictions to the amount of fluid you drink and your diet.

KIDNEY TRANSPLANT

What is a kidney transplant?

A kidney transplant is when a healthy kidney is removed from a human donor and then placed inside your body during an operation. The new kidney is connected up to your own blood vessels so that the blood can go through the kidney to be filtered. The new kidney is also connected to your bladder where the urine that it makes goes.

- A successful transplant is the best treatment for most people with kidney failure. People who have a successful transplant have a better quality of life and tend to live longer.
- Having a successful kidney transplant means that you will not need to have dialysis.
- After a transplant, there are lots of different medicines to take to stop your body from rejecting the new kidney. You will need to take this medicine every day.
- A kidney transplant takes over many of the functions of the kidney, unlike dialysis which is only able to remove toxins and excess fluid.
- The new kidney usually starts working almost immediately. Sometimes though, it may take a few days to start. Occasionally, it may never work. If the kidney transplant doesn’t work straight away or at all, you will need to have dialysis.
- Kidney transplants keep working for about 10 years.[7]
- If the kidney transplant stops working, you will need to have dialysis, or another transplant.
- Unfortunately, not all patients are suitable for a transplant. The doctors will assess each patient carefully, before a transplant is considered.



Where do the kidneys for a transplant come from?

There are two sorts of donors who can give a kidney for a transplant:

Living donors

> Someone who is alive can donate a kidney to you. This can be a family member, husband or wife, a good friend or even someone you may not necessarily know.

Cadaver donors

> These donors have decided to donate their kidneys after they die.

How does a kidney transplant work?

- First of all, a donor kidney needs to be found. Finding a suitable kidney is different depending on whether it is a living donation or cadaveric donation.
- If you would like a living donor kidney, you will need to find an appropriate match. The living donor will need to have a lot of health checks before they are allowed to donate their kidney, to make sure it is safe for them and for you.
- Having a cadaveric kidney means waiting for a suitable kidney to become available. Kidneys from cadaveric donors are given to the best matched patient.
- While you are on the transplant waiting list, you need to be reachable 24 hours a day and be able to get to the hospital fast.
- If you have a living donor transplant you may not need to wait as long as you would for a cadaveric kidney.
- If you have a living donor transplant, both you and the donor need to be assessed.
- Before the operation, a cross-match will be performed to make sure that your body does not reject the new kidney. If the cross-match is negative it means the transplant operation can go ahead.
- The kidney transplant operation takes approximately 3 hours and most of the time the transplant kidney will start to work immediately. Sometimes the transplanted kidney doesn't work straight away and dialysis might be needed for a short period.
- After the transplant operation you will have to go to the hospital every few days to check the kidney is working and to adjust the medication. Over time these visits will decrease and eventually you may only need to visit the hospital once a year.

Facts about all donated kidneys >>>

The donor must not have any serious health issues (ie. cancer), or major infections (ie. hepatitis, AIDS).

The donors blood type and body tissues must match with the patients'.

A living donor must be an adult, aged 18 or older.

CONSERVATIVE MEDICAL TREATMENT

Some people with kidney failure may have lots of other serious health issues. For these people, having dialysis or a transplant may not make them feel any better, or improve their quality of life.

Therefore some people may choose not to have dialysis or a transplant.

> If you decide not to have dialysis or a transplant it is important to discuss this with your doctor and your loved ones.

> The healthcare team will provide support to you and your loved ones while you make that decision.

> Sometimes it may not be clear if the benefits outweigh the burden of the dialysis. In this case you could start dialysis for a trial period and make your decision after that.

> Not having dialysis may shorten your life. How long you live will be different for different patients. This will depend on their overall medical condition and the amount of kidney function they have left.

> Some people with kidney failure who need dialysis but choose not to have it may live for weeks, months, or years without dialysis.

If you choose not to have any dialysis, continuing medical care is still important. This will include:

> **Diet** – patients who are not going to receive dialysis will benefit particularly from paying attention to what they eat.

> **Anaemia management** – many people with kidney failure become anaemic. It's possible to treat anaemia with an injection called EPO (erythropoetin).

> **Blood pressure** – controlling blood pressure can help slow down kidney failure.

> **Symptom control** – many treatments are available to control your symptoms you might experience;

- Tiredness and drowsiness
- Feeling sick and being sick this can be helped with diet and medicines
- Fluid build-up this can usually be helped with tablets and by not eating too much salt

FREQUENTLY ASKED QUESTIONS

Q: When should dialysis be started?

A: It is recommended that you start dialysis before you have any severe symptoms or complications of kidney disease. Your doctor will advise you.

Q: Can the need for dialysis be delayed?

A: It may sometimes be possible to delay the need for dialysis by controlling blood pressure, eating a special diet, and taking medication prescribed by your doctor.

Q: Will dialysis or a transplant solve the problem?

A: Neither dialysis nor a kidney transplant can cure a kidney disease, however treatments are very effective at making symptoms better and prolonging your life.

Q: Where is dialysis performed?

A: Dialysis can done either at home, or at the hospital. At home you can choose between haemodialysis (HD), or peritoneal dialysis (PD). Treatment in hospital is only HD.

Q: Which treatment is the best – haemodialysis or peritoneal dialysis?

A: Over the long term both types of dialysis are effective and should be chosen based on what suits you best, both clinically and to fit in with your lifestyle. A lot of patients will try different types of dialysis, which is normal, as your needs change. You can discuss how you are feeling with your renal team regularly, to make sure that you are on the best treatment for you at the time.

Q: What do I need to do to take care of myself?

A: Learn as much as possible about your treatment. When you understand the benefits of following a special diet, taking medication, and having dialysis you will feel more in control and more confident in adapting to this new lifestyle. It is also important for you to return to as many of your past activities as possible. Getting back into old routines will help you to feel that sense of normality again.

THINGS TO THINK ABOUT WHEN MAKING YOUR DECISION

- There is currently no cure for chronic kidney disease
- You will need treatment for the rest of your life
- You can change treatment if it is medically suitable for you
- You may need different treatment options during your life as a chronic kidney patient
- Sometimes the doctors and nurses may recommend a change of dialysis option for medical reasons
- Overall, both methods of dialysis (HD and PD) are equally effective in the long term, however, some doctors feel that starting on PD may offer several medical benefits over HD (see page 12)
- A successful kidney transplant is more effective than HD or PD but some people may not be suitable for a transplant

All treatments for kidney disease have some risks

- The most common risk is infection
- Prevention of infections will become an important part of your life on dialysis
- Some infections can be treated without needing to go to hospital

Always remember that you are not alone.

The team at the renal unit will work together with you.

They will share their knowledge to help you make the best decision to fit with your lifestyle.

IT'S YOUR LIFE.
IT IS YOUR DECISION. >>>

Scan the QR codes to visit the My Kidney Journey website:

For UK

For Ireland

Adverse Events and any suspected defective medicines should be reported.
For the UK reporting forms and information can be found on www.mhra.gov.uk/yellowcard.
For Ireland reporting forms and information can be found on www.hpra.ie

1. The Health Foundation (2011) Helping People Help Themselves. p6. **2.** Yeates K, et al Hemodialysis and peritoneal dialysis are associated with similar outcomes for end-stage renal disease treatment in Canada. Nephrol Dial Transplant 2012; 27: 3568-75. **3.** Molnar MZ, et al. Dialysis Modality and Outcomes in Kidney Transplant Recipients. Clin J Am Soc Nephrol 7: 332-41. **4.** Pauly RP, et al. Survival among nocturnal home haemodialysis patients compared to kidney transplant recipients. Nephrol Dial Transplant 2009; 24(9): 2915-9. **5.** Chertow GM, et al. In-Center Hemodialysis Six Times per Week versus Three Times per Week (The FHN Trial Group). N Eng J Med 2010; 363(24): 2287-300. **6.** Walsh M, et al. The effects of nocturnal compared with conventional hemodialysis on mineral metabolism: A randomized-controlled trial Hemodial Int 2010; 14(2): 174-81. **7.** UK Renal Registry 18th Annual Report: Chapter 2 UK Renal Replacement Therapy Prevalence in 2014: National and Centre-specific Analyses.

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