

Dialysis: making the right choices for you

The Dialysis Decision Aid Booklet

Dialysis Decision Aid

This booklet is for people who have, or know someone, with chronic kidney disease. It aims to help people make a decision about which dialysis treatment fits best into their life.

The spaces in this booklet are for people to jot down notes important to them about their life and living with kidney disease. These notes will help the conversations people have with family and health professionals about the dialysis decisions.

Many people write their name in the space below. Knowing who a booklet belongs to means we can return it, if it gets left behind in clinic.

Name: 

Kidney Unit:

This booklet may be given to you as part your kidney unit or pre-dialysis education service. The details of your kidney service are:

Team Members: 

Address and contact details:

The making of this Dialysis Decision Aid Booklet

The Kidney Research UK Dialysis Decision Aid was developed by the Yorkshire Dialysis Decision Aid (YoDDA) research team from studies of patient experiences when making dialysis decisions and leaflets given out by kidney services, patient organisations and charities. The YoDDA Team included decision scientists and health service researchers from the University of Leeds, and nurses, doctors and patients from the NHS Hospital Trusts at Leeds, Sheffield, Doncaster, Bradford, York, Hull, and North Staffordshire.

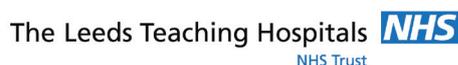
For information about the YoDDA studies, visit www.yodda.leeds.ac.uk or contact Dr Hilary Bekker (h.l.bekker@leeds.ac.uk) at The Leeds Institute of Health Sciences, University of Leeds, 101 Clarendon Road, Leeds LS2 9LJ. The studies were funded by: Kidney Research UK, in partnership with Baxter Healthcare Ltd, the British Renal Society and Renal Association, the National Kidney Federation; The Informed Medical Decisions Foundation, USA, The Yorkshire Kidney Research Fund.

Disclaimer: Every effort has been made to provide accurate and complete information at the date of publication. However, errors can occur. If you have questions, ask your doctor or kidney service.

For copies of the Kidney Research UK Dialysis Decision Aid Booklet, contact Kidney Research UK Health Information by:

- Website: www.kidneyresearchuk.org/health-information
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- Telephone: 0845 300 1499

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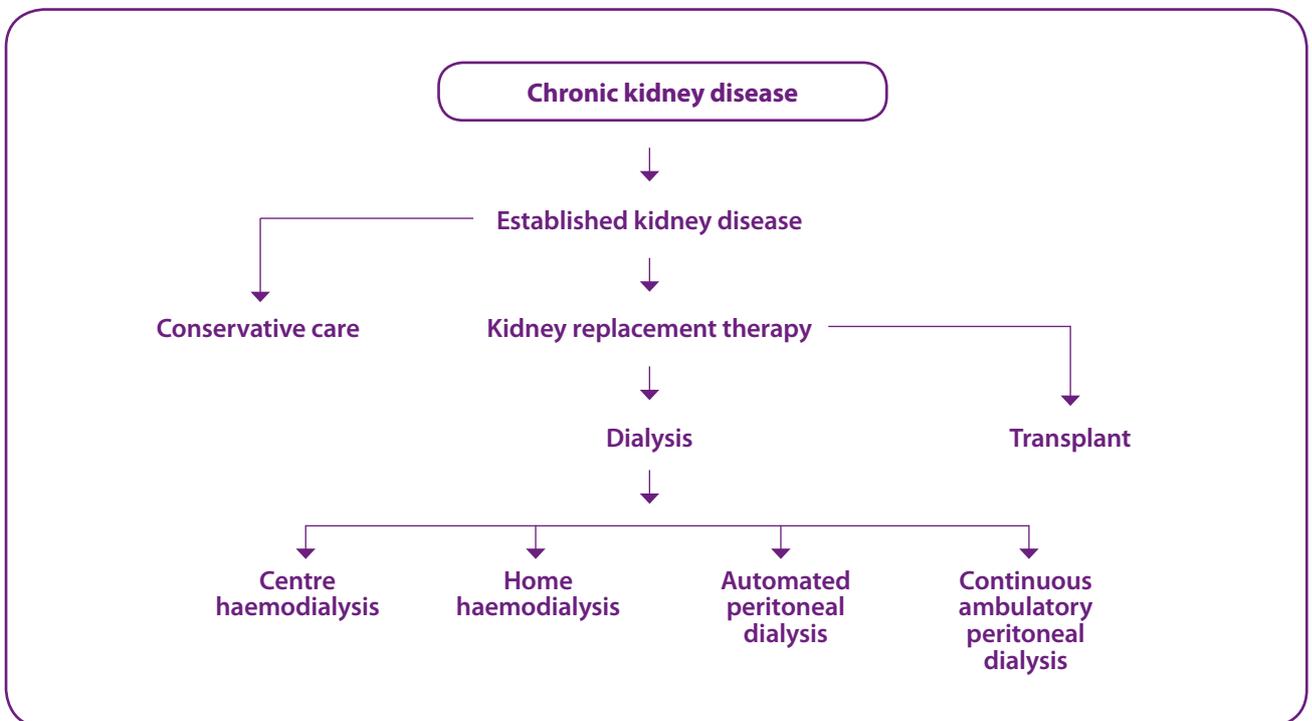
Using this Dialysis Decision Aid Booklet

People use this booklet in different ways. Most people read it a few times. Some like to read it on their own and others with family, friends or health professionals. Some people read it from beginning-to-end and others dip into chapters.

These prompts guide people through the booklet:

- **Decision maps** are pictures to help people link the information in the booklet with the decisions people with chronic kidney disease are making. The maps signpost the next topic in the booklet. For example, the map below has a purple keyline box around chronic kidney disease. The first topic in the booklet is about chronic kidney disease.
- **Content pages** list the chapters about kidney disease and dialysis with a page number in the booklet.
- **Tables** describe the features of all four dialysis options next to each other to help people compare what is the same or different about each one.
- **Making the dialysis decision** section has prompts to help people think about which dialysis treatments will fit best into their life at this time.
- **Glossary** describes the meaning of the terms health professionals use to describe kidney disease and its treatment.

Decision map 1 - Chronic kidney disease



Contents

The first three sections of this booklet have information to help people:

- Understand more about kidney disease (Section A).
- Understand the dialysis treatments (Section B).
- Think about which dialysis treatment is best for them (Section C).

The fourth section has further information about living with kidney disease and the research used to write this booklet (Section D).

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(A) Information about chronic kidney disease

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1. What is chronic kidney disease?

Chronic kidney disease (CKD) is a long-term health problem where the kidneys slowly stop working. Over time, the damaged kidneys stop working altogether. Chronic kidney disease is sometimes called chronic renal insufficiency or chronic renal impairment. “Chronic” means that it lasts months or years. “Renal” means that it has to do with the kidneys.

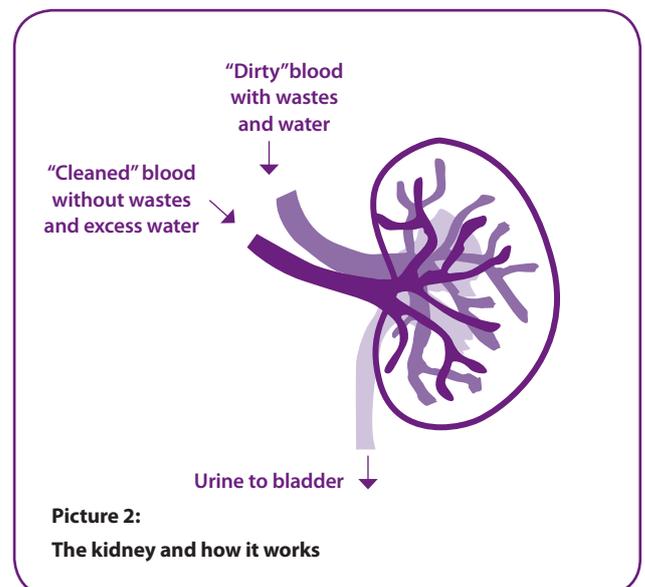
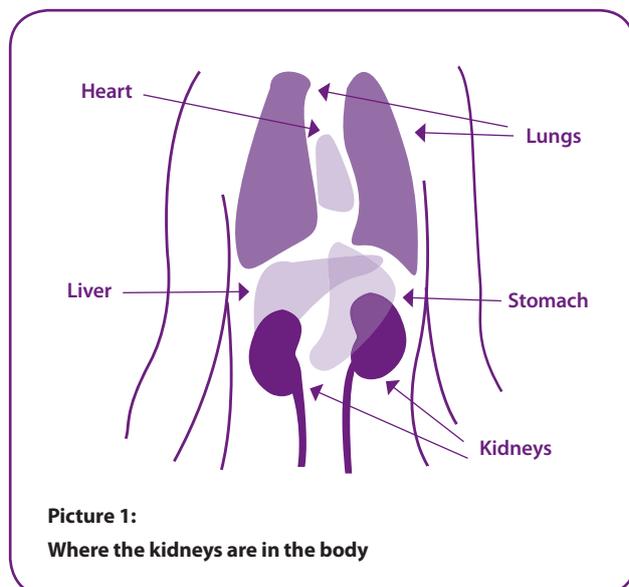
What do kidneys do?

When the kidneys are damaged permanently they cannot do their usual jobs. As a result, harmful toxins and excess fluid build up in the body. Kidneys do five types of jobs for our bodies:

- 1) Kidneys act as a filter and “clean” the blood. Waste products and excess water leave the body in people’s urine.
- 2) Kidneys control the levels of water and different minerals needed for good health e.g. salt, sodium and potassium.
- 3) Kidneys make hormones to control other bodily functions such as blood pressure and anaemia.
- 4) Kidneys keep the acid-base levels of the blood constant.
- 5) Kidneys control the body’s calcium levels and bone health.

Where are the kidneys?

Most people are born with two kidneys. Kidneys are internal organs that lie on either side of the spine in the lower back (picture 1). The kidneys are reddish in colour and shaped like kidney beans. Each kidney is about the size of a clenched fist (picture 2).



What causes chronic kidney disease?

About 8 people out of every 100 (8%) in the UK have chronic kidney disease (CKD). As people get older, they are more likely to get CKD. People are more likely to have CKD if they are South Asian or Black African. Many diseases can cause the kidneys to stop working properly. The most common causes are **diabetes** and **high blood pressure**.

Other illnesses that can damage the kidneys are:

- Inflammation of the kidney (glomerulonephritis).
- Reflux nephropathy (when urine flows backwards into the kidneys).
- Genetic (inherited) problems such as polycystic kidney disease (PCKD).
- Long term use of painkillers and some other drugs.
- Autoimmune disorders (when a person's immune system attacks the kidney as if it were not meant to be there).

Symptoms of chronic kidney disease

Usually people with early stage chronic kidney disease have no symptoms and feel quite well. As the disease gets worse, people can experience some symptoms: weakness; tiredness; itching; loss of appetite; headaches; weight loss; nausea; swollen ankles and/or hands. People often find out they have chronic kidney disease when it is quite advanced because these symptoms are common in older people and/or people who do not have kidney disease. Most people only find out they have kidney disease because of tests done by the doctor.

How people with chronic kidney disease look after their health

People with chronic kidney disease have regular appointments with specialist health professionals in hospital-based kidney services. The kidney services give advice about staying as healthy as possible and carry out routine tests to check how the kidneys are working (see progressive chronic kidney disease, page 11).

A doctor with knowledge about kidney disease is called a nephrologist. People with chronic kidney disease see nephrologists regularly to check their kidney function and general health. They may also see other specialists like a transplant co-ordinator, and/or a palliative care doctor. Other health professionals supporting people to manage their chronic kidney disease are:

- Nurses and nurse specialists in kidney disease and dialysis provide advice on managing kidney disease, medications, and other treatments.
- Dieticians provide advice about food, drinks and nutrition.
- Social workers work with some kidney units to help people with kidney disease find the right type of benefits to support their treatment.
- Counsellors or clinical psychologists work with some kidney units to help people adjust and cope with their kidney disease, and its management.

2. What is progressive chronic kidney disease?

People are described as having progressive chronic kidney disease when tests carried out by the kidney service show the kidneys are getting worse. The speed at which the kidneys get worse varies from person to person. Taking medication and making lifestyle changes can also slow down the speed at which kidneys get worse. When the kidneys' functions get worse, health professionals say the kidneys are failing.

Kidney services ask people with progressive chronic kidney disease to make a decision about how best to manage their kidney disease in the future. People are asked to choose between treatments that can do some of the work of the kidneys, *kidney replacement therapy* (renal replacement therapy) or treatments that manage the symptoms of kidney disease, *conservative care*.

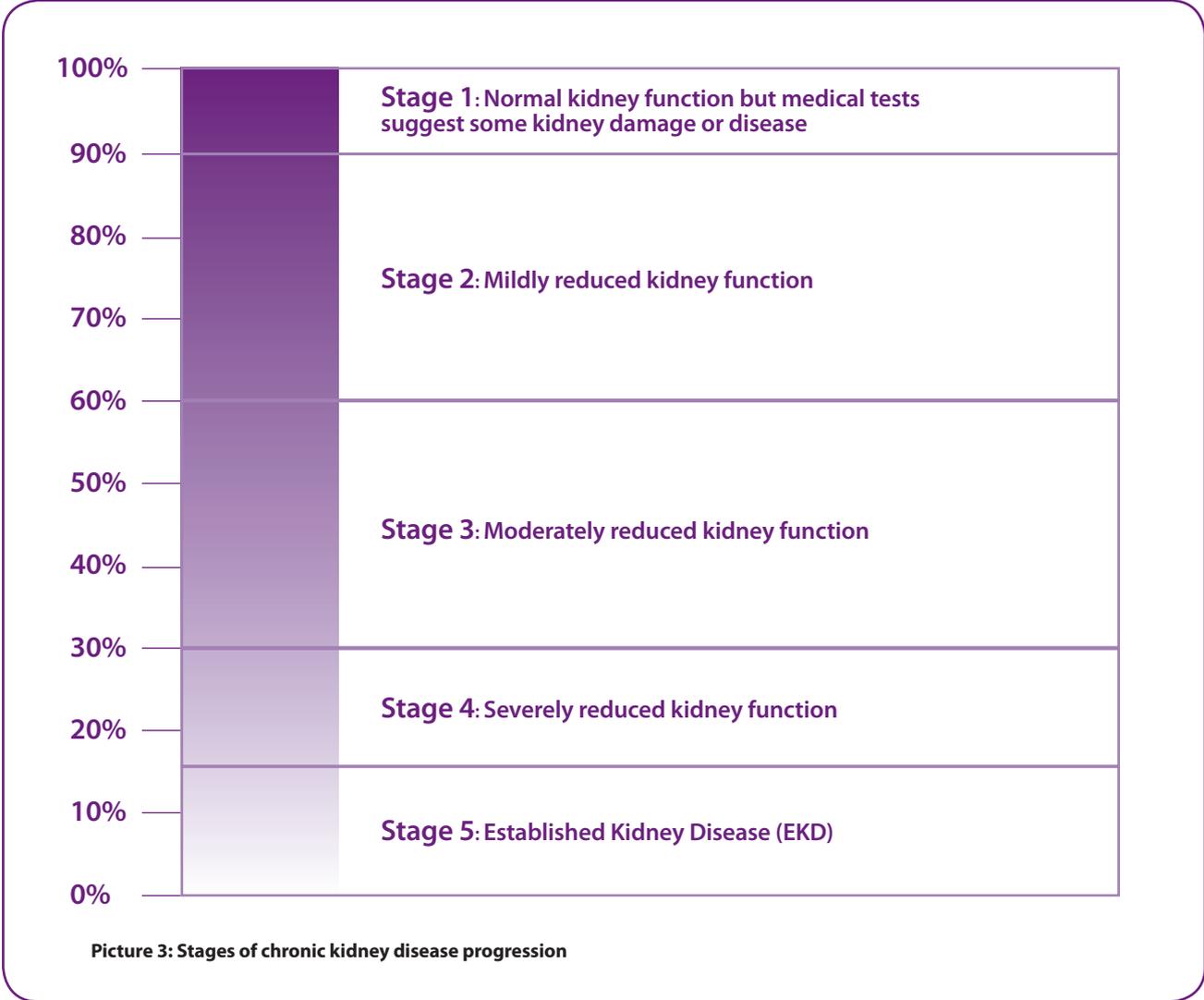
What are the stages of chronic kidney disease?

Chronic kidney disease is split into 5 stages. Each stage describes how well the kidneys are working. A common way to measure how well kidneys are working is the 'estimated Glomerular filtration rate' (eGFR). The eGFR shows how well kidneys filter fluid and clean the blood. When the kidneys start to fail, they are less able to clean the blood and the eGFR starts to drop. The eGFR figure is used to give patients a percentage for how well their kidneys are working (see picture 3).

How is kidney function measured?

Normally the kidneys filter 100 ml of blood a minute. Because the figure is 100, kidney function is usually described as a percentage of normal kidney function. For example, if the kidneys are not working properly and filtering only 50 ml of blood every minute, they can be said to be working at 50% (see picture 3).

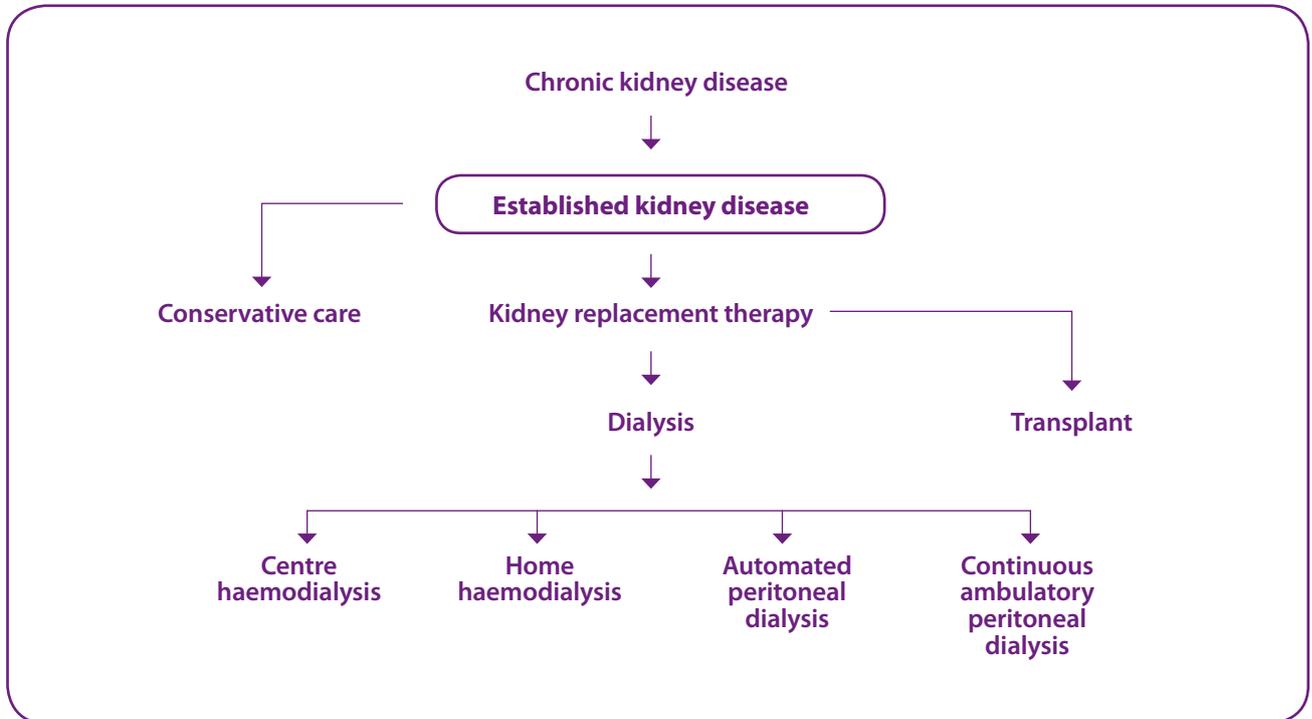
A blood test is done to measure creatinine levels. Creatinine is a waste product that the kidneys normally filter out of the blood. As kidney function starts to drop, levels of creatinine in the blood will rise. The level of creatinine is used to say how much the kidney disease has progressed.



Use the space below to note any questions you have or ask others to write down information:

3. What is established kidney disease?

Decision map 2 - Established kidney disease



When the kidneys work less than about 10-15% of their normal rate, the kidney disease is described as **established kidney disease (EKD)**. Established kidney disease is sometimes called end stage renal disease (ESRD), end stage renal failure (ESRF), established renal failure (ERF), advanced kidney disease (AKD), stage 5 CKD, or chronic kidney failure (CKF). There is no cure for people with established kidney disease. Once people have established kidney disease, they have it for the rest of their life.

Health problems of people with established kidney failure

Some of the common problems that can cause symptoms are fluid overload, mineral imbalance, and high blood pressure.

Fluid overload happens when there is too much water in the body. This happens when fluid the body gets from having a drink or food is more than the fluid taken away by urine and dialysis. Usually the first sign of fluid overload is the ankles swelling. If serious, fluid overload can cause breathing difficulties (pulmonary oedema), high blood pressure (hypertension) and heart disease. When kidneys fail, patients make less urine. Making less urine means people must drink less fluid. The amount of urine people make is measured to tell people how much liquid they can have (fluid allowance).

Mineral imbalance happens when there is the wrong amount of minerals, like potassium and phosphorus, in our bodies. The kidneys help control the levels of minerals in the blood by controlling how much of each mineral is taken out by their urine. Kidney health professionals do regular blood tests for people with established kidney failure to check the balance of minerals. They give advice about which medicines to take and what foods to eat to keep this balance of minerals in their bodies. The health problems people get when there are high levels of these minerals are:

- High blood potassium level – also known as **hyperkalaemia**. Hyperkalaemia can cause a weakness in the muscles, an irregular heartbeat (arrhythmia) and, in some people, sudden death.
- Too much phosphorus – also known as **hyperphosphatemia**. Hyperphosphatemia can cause itching, restlessness, bone disease and hardening of the arteries.

High blood pressure can cause kidney failure by damaging the way the kidneys work (see pages 8-9). Also, kidney failure can cause high blood pressure. When the kidneys do not work well, they cannot control blood pressure. As blood pressure increases, it damages the person's blood vessels. Damaged blood vessels increase the chance of a person having a stroke or heart attack. Many people with kidney disease take one or more tablets to control their blood pressure.

Symptoms of established kidney disease

Uraemia is used to describe the problem of the body not being able to get rid of its toxins and excess water. There are many symptoms that might happen because of uraemia including: long-lasting tiredness, weakness, and/or drowsiness; itchy and/or dry and flaky skin; feet, face, hands, and/or ankles swelling up; changes to the patient's breath - either shortness of breath and/or an unpleasant ammonia smell (ammonia is a chemical that smells like stale urine) and/or an unpleasant metallic taste in the mouth; loss of appetite and/or nausea; muscle cramps and/or restless legs; changes to sleeping patterns such as poor sleeping; changes to concentration and/or some additional confusion; lowered sex drive; feeling colder; high blood pressure, persistent headaches, vomiting, bruising or bleeding.

Kidney health professionals can help people with established kidney disease manage or relieve these symptoms by giving medicines, advising on lifestyle changes, and/or other treatments. These treatments will not cure established kidney disease and/or stop the kidneys from getting worse.

Getting used to established kidney disease

When people are told their kidneys are failing it affects their lives and how they feel, and also how people around them feel. People diagnosed with kidney failure often feel shock, grief and denial at first. It is common for people to experience anxiety, depression, concerns with body image, loss of self-confidence, and a loss of interest in sex. Some people find it difficult to concentrate and think clearly. Many people have sexual difficulties. Impotence is the most common sexual problem, but treatment is usually successful.

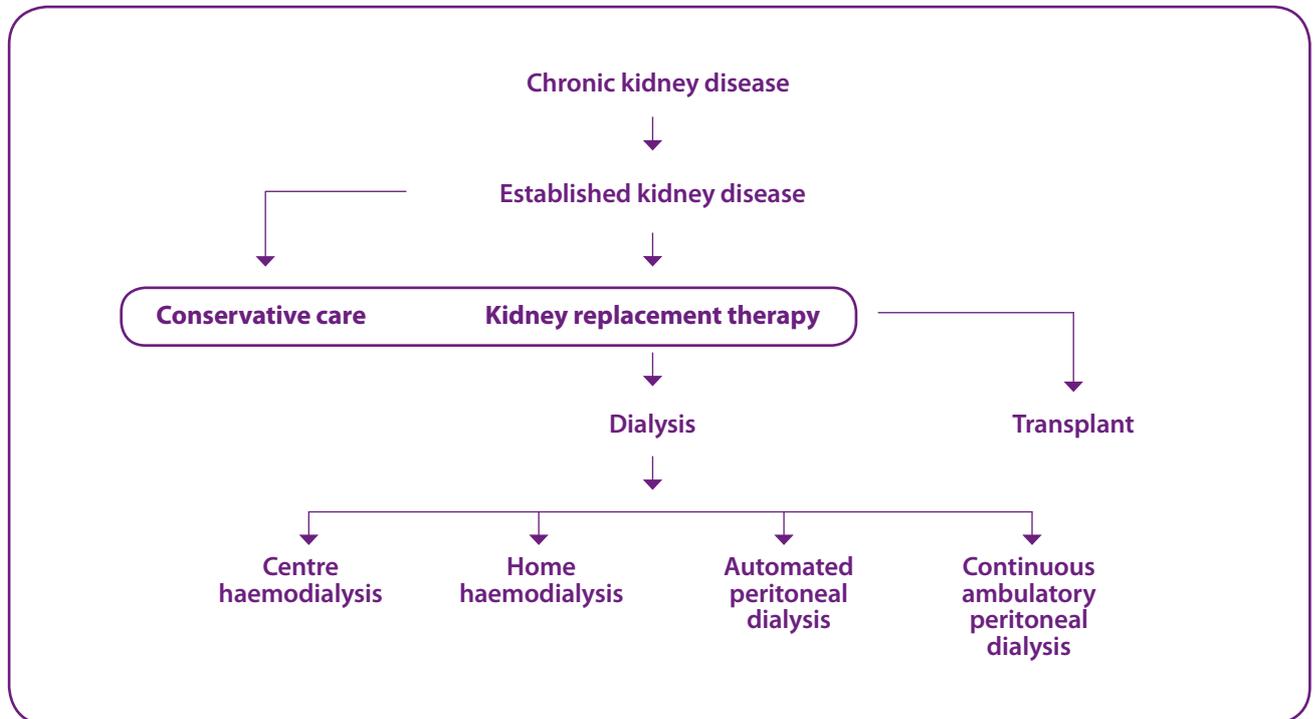
People find that knowing more about kidney failure and the treatments available helps them cope with it better. Some people find sharing their experiences and feelings with other patients, friends and family helps. There are many health professionals to support patients, such as kidney nurses, the clinical psychology team, social workers and doctors. Different services offer this support in different ways.



Use the space below to note any questions you have or ask others to write down information:

4. Treatment choices for established kidney disease

Decision map 3 - Conservative care, kidney replacement therapy



People who are told their kidneys are failing are asked to make a decision about how they want to start managing their established kidney disease. The treatment choice they make will change how they manage their kidney disease on a day-to-day basis. As established kidney disease is a life-long condition, people may change their treatment choice as their disease and life changes. It is likely people will make different decisions at different points in their life.

The first decision to make is between a treatment that does some of the work of the kidneys (kidney replacement therapy) and a treatment that manages the symptoms of kidney disease (conservative care):

Kidney replacement therapy - a treatment plan that does some of the work of a kidney, also known as renal replacement therapy (RRT). The types of kidney replacement therapy are:

- **Dialysis:** the treatment uses equipment to clean your blood and do some of the work that healthy kidneys do. Dialysis does about 10% of the work of healthy kidneys. This amount of dialysis improves some of the symptoms of kidney disease. The person's failing kidneys will keep getting worse.
- **Kidney transplant:** a person without kidney disease (donor) gives a kidney to a person with failing kidneys (recipient) during an operation. The transplanted kidney does about 50% of the work of two healthy kidneys. This amount of work controls the symptoms of kidney disease. The person's failing kidneys will keep getting worse.

Conservative care - a treatment plan that treats the symptoms of established kidney disease. Conservative care does not replace the work of kidneys. The person's failing kidneys will keep getting worse.

Conservative care treats the symptoms of having established kidney disease using medications, lifestyle changes and other treatments. Conservative care keeps a person's kidneys working for as long as the kidney disease allows. People who decide to have conservative care instead of a kidney replacement therapy often have other medical conditions or are very frail. They often feel that the day-to-day effort of having dialysis does not outweigh its benefits of managing the disease.

Some people who choose conservative care will die of another illness before their kidney failure leads to death. For others, the kidney failure will mean people die sooner as a result of their kidney disease.

Kidney transplant means a kidney from another person is put inside the body of a person with established kidney disease during an operation. The transplanted kidney can be from a person you are not related to (living donor), a person from your family (live-related donor - LRD), or a person who has died (deceased brain dead - DBD or deceased cardiac death - DCD). Not all people with established kidney disease can have a kidney transplant. About 45 people out of 100 (45%) are medically unsuitable. For someone to have a transplant, a medically appropriate donor needs to be matched to the person with kidney disease.

The operation is done by surgeons. Usually, the transplanted kidney is put below the failing kidneys. The transplanted kidney does all the jobs a kidney needs to do to keep the body healthy. One transplanted kidney does enough work to mean people do not have to restrict their diet and fluid in the same way as before the operation. After a kidney transplant, people take medication for the rest of their lives to stop their body (immune system) from rejecting the transplanted kidney. Most people who have transplants have a better quality of life and survival rate than those on dialysis.

Many people with chronic kidney disease put their names on a transplant list and wait for a donor. People can be on the list for a long time. Many people on the list will be asked to decide which type of dialysis to have whilst they wait for a kidney match. About 33 in 100 people on dialysis are on the transplant waiting list. About 15 of the 33 will have a transplant. Sometimes the transplanted kidney does not work. People whose transplanted kidney starts to fail are asked to make a decision between another transplant, dialysis treatments and conservative care.

Thinking about the decision between kidney replacement therapy and conservative care.

People’s lifestyle, family life, and experience of illness means they may value one of these treatment choices more than another. On page 42, there are questions to help you think about what is important to the way you live your life now and what you might think of changing. Ask your kidney professionals if there is something about your lifestyle that makes one treatment fit better in your life than another.

People’s kidney disease, other health problems, and how healthy the person with established kidney disease may mean one treatment is medically better than another. Some people’s medical history means they are not able to have a kidney transplant or one type of dialysis. Ask your kidney professionals if there is something about your medical history that makes one treatment medically better for you than another.

The rest of the information in the booklet is for people who are thinking about choosing a dialysis treatment.



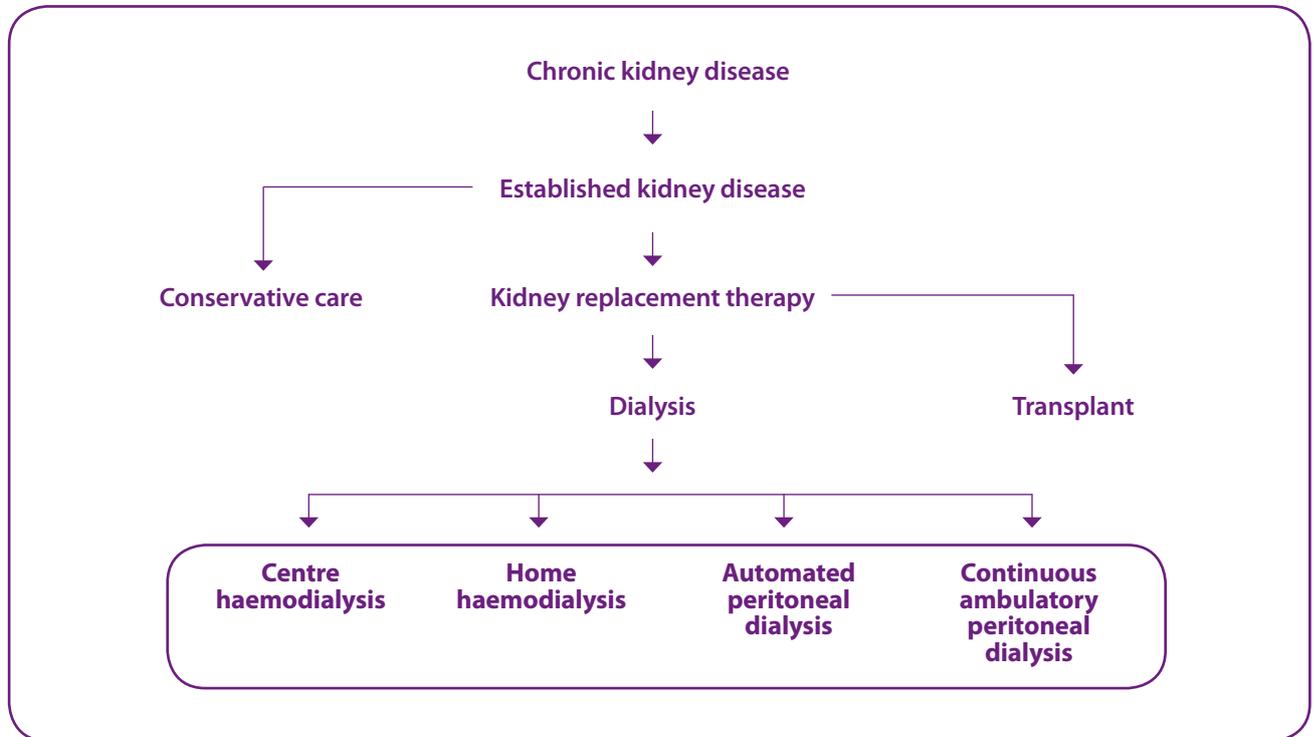
Use this space to write down any thoughts or questions you have:

(B) Information about dialysis options

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5. Introduction to dialysis treatments

Decision map 4 - Dialysis treatments



The booklet describes four dialysis treatments. For most people, each dialysis treatment works as well as each other to remove toxins and fluids from people’s bodies. There are advantages and disadvantages to all dialysis options. Each person’s life is different so people need to think about which treatment option suits their life best. Some people say it is useful to read about all four options before making a decision. Some people found it helpful to talk about this information with their families and friends, or give them the booklet to read.

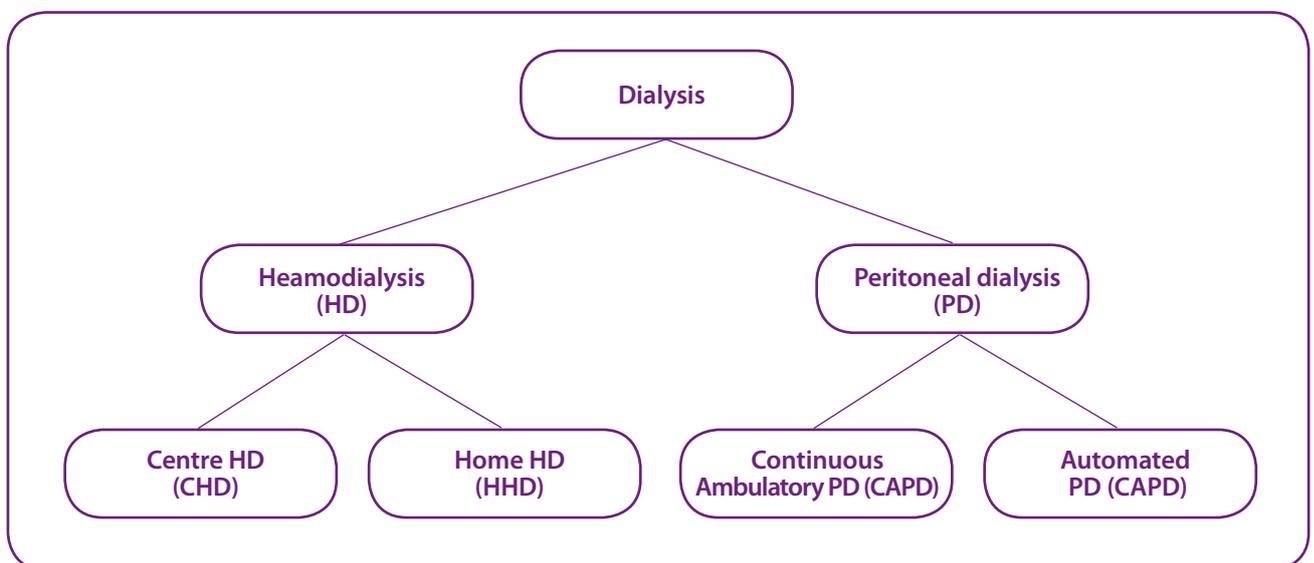
What is dialysis?

Dialysis is a treatment for people whose kidneys have almost completely stopped working. Dialysis treatments use equipment to do about 10% of the work that healthy kidneys do. This percentage means enough toxins and fluids are removed from the body to keep it working. Dialysis takes away toxins and excess water from patients’ body by using either a) a machine to pump blood outside the body (haemodialysis) or b) a liquid that is added and removed from the belly (peritoneal dialysis).

Dialysis does not cure the chronic kidney disease. Failing kidneys will keep getting worse. Most people with established kidney failure who have dialysis treatments live longer than people who have conservative care. People who start on a dialysis treatment will have dialysis for the rest of their lives, or until they have a successful kidney transplant. People may decide to switch to another type of dialysis treatment as their lives or health changes.

Types of dialysis

People who choose dialysis are asked to make a decision between different dialysis treatments. There are two types of dialysis treatment, each offered in two different ways: Haemodialysis (HD), offered in a specialist centre (CHD) or at home (HHD), and Peritoneal Dialysis (PD), offered in a Continuous Ambulatory (CAPD) or Automated (APD) form at home.



For most people each treatment is equally good at removing waste products from the body. The dialysis treatments differ slightly in (see table summary page 40):

- The equipment used to remove the waste.
- Where on the body the access point is made to allow the treatment to work.
- Where patients can carry out the dialysis session.
- How often dialysis sessions must be carried out.
- How long a dialysis session lasts.

The exact number of dialysis sessions (frequency) and length of dialysis sessions depends on how well each of the kidneys is working when people start dialysis. People on dialysis have regular blood tests to work out the frequency and length of their dialysis sessions.

Dialysis and life expectancy

The life expectancy of patients with established kidney disease is less than the life expectancy of healthy people. Once on dialysis, the life expectancy of patients on dialysis is affected by the same factors as patients who are not on dialysis. The most common cause of death for people on dialysis is from another illness they may have such as cardiovascular disease, diabetes or infection, and not the kidney disease itself.

Many studies have been carried out tracking the life expectancy of patients on different types of dialysis. Scientists have compared groups of people having different types of dialysis to see if one type of dialysis is better than another. It does not seem that one type of dialysis results in a longer life expectancy than another. It is difficult to do studies to answer this question because people who have chronic kidney disease start dialysis at different ages and have different types of other illnesses.

The best chance of living longer on dialysis is to plan the dialysis therapy as soon as possible with the kidney professionals. People who decide and start on a treatment as their kidney function begins to fail live longer than people who start dialysis late, after their kidneys have failed.



Use this space to write down any thoughts or questions you have:

6. Thinking about the dialysis decisions

Read and think about all four options before deciding which one you want to try at this time. Knowing why you felt one dialysis treatment suited you better than another will be useful when deciding on the dialysis treatment you like best.

For most people all four dialysis options work equally well. All dialysis options have side-effects, longer term health problems and are equally life-changing. People need to think about which dialysis treatment fits best into their life. Kidney health professionals will meet with people making this decision and their families to help make sure the dialysis treatment chosen fits in with their lifestyle.

Most people will be able to have the dialysis treatment they prefer. However, some kidney services do not offer all four dialysis treatments. Some people have a medical reason which means one dialysis option is better for them than the other. Many people with established kidney disease will have more than one type of dialysis during their lives.

When to make a choice?

When people are told their kidneys are getting worse, they do not know how long it will take until they fail. People need to make the decision about which type of dialysis to have before their kidneys fail, for the following reasons:

- a) To decide themselves which dialysis treatment is best suited to their lifestyle.
- b) To allow kidney services to plan for changing the management of people's kidney disease. Kidney services work with other support services to make sure all the home and hospital changes are in place before people start their dialysis treatment.
- c) To give the surgeons a chance to carry out an operation to make an access point in people's bodies. Before people can use the dialysis equipment, they need to have an access point so that the toxins and fluids can be taken out of their bodies. It may take up to 8 weeks to make an access point. Sometimes this operation needs to be done more than once because the first access point did not work.
- d) A person's health is better if dialysis is planned and started before the kidney's fail. People with established kidney disease who do not plan and start dialysis before their kidneys fail may need an emergency or unplanned dialysis procedure.

Talking about dialysis with family, friends and kidney professionals

Many people find it useful to talk with family and friends about what is important to them about their lifestyle, health and different dialysis treatments. Different people have different questions or worries about the dialysis treatments. Talking through this decision with family members helps people explain to kidney professionals what is important to them about this decision, and why.

The specialist dialysis teams give information, training and support to people making decisions about dialysis. They talk with people, and their families, when making this decision to understand which dialysis option will fit best into that person's lifestyle.

Other patients' experiences of dialysis

Some people find it useful to hear other patients' stories of living with dialysis. Some people talk to patients about their kidney disease whilst waiting for their appointments during routine hospital visits. Although others' experiences of dialysis and established kidney disease can help people live with being on dialysis, everyone's life is different. The reasons that one type of dialysis is right for one person may not be right for another.

All kidney services provide some information to help patients make a decision about dialysis services. Most will have information about support groups in their service for people with chronic kidney disease to meet and talk about living with the disease. Some kidney services arrange for people on dialysis to talk with new patients about the different dialysis treatments.

Adjusting or switching dialysis treatment

After people start dialysis, they often make adjustments or changes to their treatment. Some patients change details about their dialysis but stay on the same type of dialysis treatment. Some patients change the type of dialysis treatment that they receive. People may do so for two main reasons:

- A person's kidney disease and health changes over time. For example, some people's kidney disease gets worse, they get another health problem or there is a complication from the dialysis treatment they have chosen.
- A person's home, work, social or personal situation changes. For example, some people stop working, move home, get different hobbies or have different people living in the home with them.

7. Common features of dialysis

This chapter has information about those features of dialysis that are the same for all four treatments.

Contact with health professionals

People on dialysis will be seen regularly by their kidney health professionals when they go to hospital for their kidney disease check-ups. People on dialysis will also see regularly the specialist dialysis team to check on how well their dialysis is working for them. The dialysis health professionals have experience on how to help people manage their dialysis and kidney disease at home, on holiday, around special occasions and hobbies, and will help them learn to live with dialysis.

Operation for the access point

People on dialysis need to have an access point made to take the fluid carrying the waste and toxins out of people's bodies, and clean fluid put back in. People will have an operation to make the access point. The access point operation fits a fistula or catheter to a person's body to make an entry point in the skin that usually lasts for as long as a person has dialysis. These operations are surgical procedures. People will need an anaesthetic when these access points are made. Surgery may need to be carried out more than once to make an access point that works well.

Caring for the access point

People must keep their access point clean. Kidney healthcare professionals help people learn how to carry out dialysis safely and keep the access point clean. If bacteria get into the access point, the bacteria can cause a serious infection. Most infections can be treated if caught early. If the bacteria are not treated, they can grow and spread through the whole body causing blood poisoning, which can sometimes be fatal.

Dialysis-related complications

There are dialysis-related side-effects that are unpleasant and can be serious, although most can be prevented or treated.

- Infection which happens when bacteria gets into the body through the access point. If untreated, infections can spread through your whole body. Signs of infection are: redness, warmth, tenderness, pain, or pus around the access point; a fever, shivering or cloudy dialysis fluid. Treating an infection may mean taking antibiotic pills or this may mean taking antibiotics through an intravenous drip in the hospital. Sometimes it may mean surgery to clean out the infection, or to make a new access point. Keeping the access point clean can often stop the infection happening.

- Blockages in the access point, which means the dialysis treatments cannot work properly. For patients on haemodialysis the arteriovenous fistula can get blocked, for people on peritoneal dialysis the peritoneal catheter can get blocked and stop working.

Health problems faced on dialysis

People starting on a dialysis treatment take time to adjust to all the changes it brings. There are some common problems people may get when they have dialysis including fluid overload, high blood pressure, and adjusting to the dialysis routine. Kidney healthcare professionals help people get used to these and other problems of being on dialysis, like feeling restricted in terms of diet and fluid intake, disliking their appearance, feeling uncertain about the future, and feeling they are a burden to other people they are close to, such as family and friends.

Changes to how people manage their chronic kidney disease

Dialysis is an extra treatment people need to fit into their daily routine to manage their established kidney disease. It takes time for people to work out how their dialysis routine fits in with their home, work, family, hobbies and social activities. All people having dialysis are seen by a specialist team at hospital, and in their homes, to help make the changes needed to their food, drink, and medicines.



Use this space to write down any thoughts or questions you have:

Changes to diet and the amount of liquid a person can drink

These changes are worked out with a dietician and kidney health professionals. The kidneys help make sure the body takes the right amount of energy and goodness from food and drink so that it can work well. A person's diet will depend on their weight, body size, and other illness.

Changes to medicines and vitamins

These changes are worked out with a kidney health professionals. Excess minerals are removed by dialysis but soon build up in the body after the dialysis session is over. Below are some of the medications patients with kidney failure may need to take:

- Vitamins and iron tablets.
- Tablets called phosphate binders to stop the body taking in too much phosphate from food and drink.
- Injections of erythropoietin (EPO) to help the body make red blood cells.
- Tablets to control blood pressure.

Changes to food and drinks

Most people are asked to avoid foods high in sodium, potassium, or phosphorous. What people can eat differs from person to person.

- Foods high in sodium include: ready-to-eat meals (including ready-to-eat sandwiches); bacon; ham; smoked fish, and cheese. People should also avoid adding salt to meals.
- Foods high in potassium include: bananas, baked potatoes; oranges, and chocolate.
- Foods high in phosphate include: dairy products, such as cheese and yogurt; baked beans, lentils, sardines, and bran cereals.

Most people are asked to reduce how much fluid they drink or get through their food. This amount differs from person to person. Most people need to drink less than a litre (two pints) a day. Foods with a high fluid content include: soup; ice cream; fruit like melons, oranges, and tomatoes. Some forms of dialysis mean people need to drink less than half a litre a day. Most people find these limits on the amount they can drink extremely challenging.

8. Differences between dialysis treatments

This table summarises information about haemodialysis and peritoneal dialysis. People find it useful to understand the differences between these two types of dialysis. On page 40 is a summary of all four dialysis treatments.

	Haemodialysis (HD)	Peritoneal Dialysis (PD)
The different names	Haemodialysis filters the waste products and extra fluid from the blood using a liquid (dialysate) and an artificial membrane with a machine outside the body.	Peritoneal dialysis filters the waste products and extra fluid from the blood using a liquid (dialysate) which is placed inside the belly and then removed.
How dialysis works	<p>Blood is pumped out from the body to a machine. The machine contains several membranes that separate the blood from liquid called dialysis fluid or dialysate. The membranes filter out waste products and extra fluid from the blood. These waste products pass into the dialysate. The used dialysate is then pumped out of the machine and thrown away.</p> <p>The cleaned blood is pumped back into the body. The blood is pumped through the machine several times. It takes about 4 hours to remove the waste products and fluid from the blood. This is called a "dialysis session".</p> <p>Blood is pumped in and out of the machine quickly, and at the same time, so that the patient does not experience blood loss.</p>	<p>Blood moves around the internal organs and intestines naturally inside the body. The membrane covering these organs is called the peritoneum. There is a space in the body made by the peritoneum called the peritoneal cavity. Liquid known as dialysis fluid or dialysate is put into this space. The peritoneum is a natural filter and allows the waste products and excess water to be drawn out of the blood into the dialysis fluid. After at least 1 or 2 hours, the used liquid is drained out and thrown away.</p> <p>Fresh liquid is added. The draining out of used liquid and the adding of fresh liquid is called a dialysis session or an "exchange".</p> <p>The liquid (dialysate) is added and removed from inside a person's belly using a catheter access point.</p>

Making access points

Haemodialysis (HD)

Usually people have a fistula made in their arm. A fistula is a blood vessel that has been operated on to make it larger and stronger. The larger blood vessel makes it easier to pump blood from the person to the haemodialysis machine, and back again. Veins usually have only a small amount of blood flowing, which is too slow for the haemodialysis machines.

The fistula has to develop when it is made, so that the blood flows smoothly through it. It takes about 8 weeks for the fistula to work properly. The most common fistula is made when a surgeon joins a vein and artery together under the skin, usually in the arm. This fistula is called an **arterio-venous (AV) fistula**. A fistula made by joining a piece of tubing to a blood vessel is known as an **arterio-venous graft**.

People need to look after the fistula by keeping it clean before and after dialysis sessions, and not sleeping on top of the fistula arm, not having blood drawn or a drip installed, and not having blood pressure taken from the fistula arm. With the proper care, a fistula can last for many years.

Peritoneal Dialysis (PD)

People have a peritoneal catheter attached to their abdomen (belly). This catheter allows access to the peritoneal cavity (space) in the belly. The dialysate fluid passes through this catheter into, and away from, the peritoneal space. When a session is finished, the catheter is sealed with a cap.

A peritoneal catheter is a thin piece of soft, plastic tube about 20cm (8inches) long. A surgeon puts the tube into the belly just below the belly button (navel). About 7-10 days after the catheter operation, the stitches are taken out. The peritoneal catheter is also known as a **Tenckhoff catheter**.

People need to look after the catheter by washing their hands before touching it, cleaning around the catheter exit site, carrying out exchanges in clean places, and covering the access point so it stays clean. With the proper care, a peritoneal catheter can last for many years.

Dialysis sessions

Haemodialysis (HD)

A session is carried out by attaching the haemodialysis machine to the fistula. Blood is pumped from the person to the machine, and back again. Needles are used to take the blood out of one side of the fistula (arterial) and put it back in the other side (venous). People have plasters after a session when the needles are taken out.

Usually for haemodialysis people have at least three sessions a week, each lasting 4 hours. Some people can have haemodialysis at home or hospital. People having hospital haemodialysis need to add travel time to the length of their session.

Peritoneal Dialysis (PD)

An exchange is done by attaching a bag or machine to the catheter. The fluid in the belly is drained out, and fresh fluid added. Between exchanges, the fluid stays in the belly. People put a cap on the catheter when the exchange is finished.

Usually for continuous ambulatory PD, people make four exchanges a day, each taking 45 minutes. For automated PD people make one exchange overnight, each night. An exchange can take place in any clean place people feel comfortable with. Most people have automated PD at home.

Side-effects

Carrying out haemodialysis means having needles put into the fistula at each session. A local anaesthetic can be used to numb the arm, or leg, the needles go into. The anaesthetic makes haemodialysis less painful.

Some people feel dizzy or tired during and/or after a haemodialysis session.

Some people say it is uncomfortable having a fistula in their arm, or leg.

Carrying out peritoneal dialysis is not generally painful. Some people say there is pain when the fluid drains in and out of the belly. This pain is usually managed by changing the drains, and is short lived.

Most people feel as well during, and after, a peritoneal dialysis exchange as they did before the exchange.

Some people say it is uncomfortable having a catheter and/or fluid in their belly.

Dialysis-related complications

Haemodialysis (HD)

Problems with the access point are the most common reason for people on haemodialysis having to make extra visits to hospital.

Common problems include infection (sepsis), blockage from clotting (thrombosis), and poor blood flow (stenosis). These problems can stop haemodialysis from working.

Stenosis

Stenosis (narrowing of the blood vessels) slows the flow of blood through the access point. Stenosis usually happens slowly and there are early warning signs such as taking longer for bleeding to stop after dialysis.

Treatments for stenosis include: putting a tiny balloon into the vessel and then inflating it (angioplasty); using a metal expander (a stent) in the vessel.

Thrombosis

Blood clotting (thrombosis) may happen with haemodialysis. The blood has clotting cells called platelets. Platelets normally stick together to seal off damaged blood vessels (e.g., in wounds). They can stick to scar tissue and damaged blood vessel walls in a fistula or graft, especially around needle punctures and when the blood flow is slow. This means the fistula might stop working.

Peritoneal Dialysis (PD)

Infection is the most common problem with peritoneal dialysis is infection. Peritonitis is an infection in the abdomen (belly) which can be serious. This infection happens when infection enters the peritoneal space within the belly. Other problems include hernias, poor drainage, infection of the exit site and leaks from the catheter (see below). These problems can stop peritoneal dialysis from working.

Poor drainage and leaks

Poor drainage can happen for more than one reason. It can happen because a substance called fibrin (a protein) blocks the PD catheter.

Usually the tube can be cleared by squeezing it or by having a nurse inject medicines into it.

Hernias

A hernia is usually a visible lump in the abdomen. It can happen when an internal part of the body, like an organ, pushes through the wall of the space in the body where it sits. Increased pressure in the peritoneal cavity can lead to weakness of the stomach muscles and make hernias more likely to happen.

Hernias often have no symptoms and are only painful when people lift heavy objects, bend over, or coughing. Surgery is usually needed to fix a hernia.

Details about dialysis-related infections

Haemodialysis (HD)

Bacteraemia (sometimes called septicaemia) is an infection in the blood stream. In some people, this infection can spread to the heart valves (endocarditis) or discs in the spine (discitis). These more serious types of infection are usually treated in hospital with antibiotics.

Peritoneal Dialysis (PD)

Peritonitis is an infection of the peritoneum (the membrane covering the organs in the tummy). In some people, this infection can damage the peritoneum. This more serious type of infection is usually treated in hospital with antibiotics.

Details about unusual dialysis-related illnesses

Some people's heart valves and discs get damaged by the dialysis-related infections. This damage means the heart or spine do not work as well as before. The treatment for this damage usually includes surgery and antibiotics. There is a chance people will die when they are treated for this damage.

Some people get encapsulating peritoneal sclerosis (EPS). The EPS means the peritoneum gets thicker and hardens because it is being coated in calcium. This coating means the peritoneum stops working properly. The treatment usually includes surgery and steroids. There is a chance people will die when they are being treated for EPS.

(C) Making the dialysis decision

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9. Comparing all four dialysis treatments

This table compares features of all four dialysis treatments. What some people like about the way dialysis is carried out may be different from what other people like.

	Haemodialysis (HD)		Peritoneal Dialysis (PD)	
	Haemodialysis at a hospital or centre (CHD)	Haemodialysis at home (HHD)	Peritoneal Dialysis Continuous Ambulatory (CAPD)	Peritoneal Dialysis Automated (APD)
Place of dialysis care	People travel to a hospital or specialist centres for dialysis session.	People have dialysis sessions at home.	Most people choose dialysis sessions at home or work. Can be any clean place.	Most people choose dialysis sessions at home or work. Can be any clean place.
How dialysis works	Attaching to a machine for 4 hours per session by the arm or leg.	Attaching to a machine for 4 hours per session by the arm or leg.	Attaching to a bag of fluid for about 40 minutes per session by the belly.	Attaching to a machine for about 9 hours per session by the belly.
Usual number of sessions in a week	3 days in a week	At least 3 times a week (night or day)	Every day	Every night
Usual number of sessions in a day	1 session per day	1 session per day	4 sessions per day (exchanges)	1 session per day
People carrying out dialysis	Staff at the hospital or centre carry out the session.	The person is trained to carry out the session.	The person is trained to carry out the exchange.	The person is trained to carry out the exchange.
Assisted and shared dialysis	In some centres, people may be trained to self-manage aspects of the dialysis session. (Shared CHD)	A carer can be trained to carry it out. A carer may be family or friend, or nursing assistant. (Assisted HHD).	A carer can be trained to carry it out. A carer may be family or friend, or nursing assistant. (Assisted CAPD).	A carer can be trained to carry it out. A carer may be family or friend, or a nursing assistant. (Assisted APD).

	Haemodialysis (HD)		Peritoneal Dialysis (PD)	
	Haemodialysis at a hospital or centre (CHD)	Haemodialysis at home (HHD)	Peritoneal Dialysis Continuous Ambulatory (CAPD)	Peritoneal Dialysis Automated (APD)
Usual time of dialysis	Most sessions are during the day; a few offer night sessions. Most people sit or lie on a couch or bed. Most read, listen to music, watch TV or sleep in sessions.	Most people usually choose day time. Most people sit or lie on a couch or bed. They tend to read, listen to music, watch TV or sleep during sessions.	Most people choose to have exchanges in the morning, and before lunch, dinner, and bed. Most people sit or stand during exchanges.	Most people usually choose night time. Most people are asleep.
Equipment needed	A machine outside the body. The machines are set-up next to patient beds or reclining chairs all the time.	A machine outside the body and dialysate fluid. The machine is usually the size of a large chest of drawers.	Bags to take away the used dialysate and bags with the clean fluid. A hook to hang the bag of fluid during an exchange.	A machine outside the body and dialysate fluid. The machine is usually the size of a small suitcase.
Changes to the home	The hospital or specialist centres have dialysis machines plumbed in, next to beds or reclining chairs.	The machine is plumbed into a person's home. Storage is needed to keep the machine, bed or reclining chair and supplies.	Storage is needed at home to keep the bags of dialysate fluid, like a cupboard or clean space in a shed, basement or garage.	Storage is needed at home to keep the machine and supplies, like a cupboard or clean space in a shed, basement or garage.
Kidney Service Support for dialysis	They organise transport for people to get to dialysis sessions and help plan care when people have trips away from home.	They organise the machine delivery, changes to the home, and plan care for when people have trips away from home.	They organise bag deliveries, changes to the home and plan care when people have trips away from home.	They organise equipment deliveries, changes to the home and plan care when people have trips away from home.

10. Making the dialysis decision

This chapter asks you to write down what is important in your life at this time, your views about the dialysis options, and which treatments you think will fit best into your life. People find it useful to talk about these views with their kidney team and family.

1. List the activities you do now and want to keep doing when you are on dialysis.



Socialising (e.g. with friends and/or family)

Hobbies (e.g. gardening, fishing, music, knitting)

Leisure (e.g. walking, cycling, swimming, sport)

Holidays, Trips Away (e.g. locally, abroad)

Local travel (e.g. public transport, driving)

Household (e.g. cooking, washing up, housework)

Looking after others (e.g. caring for family, pets)

Relaxing (e.g. sleeping, watching TV, religion)

Self-care (e.g. toileting, bathing, dressing, hair)

Study (e.g. evening classes, writing, reading)

Work (e.g. job paid, voluntary)

2. List the questions or worries you have about dialysis treatments



The access point

(arm, leg, belly)

The place of dialysis

(home, hospital, work, trips away)

The timing of sessions

(days, length, night, day)

Carrying out dialysis

(side-effects, setting it up, travelling)

Kidney service support on dialysis

(getting to hospital, support at home)

Other

(write down anything else)

3. How much do you think each dialysis treatment will let you carry on doing the activities that are important to you?



Circle one number for each treatment.

	Not at all				Completely			
	0	1	2	3	4	5	6	
Haemodialysis - Centre (machine at hospital)	0	1	2	3	4	5	6	
Haemodialysis - Home (machine at home)	0	1	2	3	4	5	6	
Peritoneal Dialysis - Continuous Ambulatory (bag at home or any clean place)	0	1	2	3	4	5	6	
Peritoneal Dialysis - Automated (machine at home or any clean place)	0	1	2	3	4	5	6	



4. Which dialysis treatments do you think will fit best into your life, at this time?

Tick one circle for each treatment.

	Not at all	No maybe	Unsure	Yes maybe	Yes Definitely
Haemodialysis - Centre (machine at hospital)	<input type="radio"/>				
Haemodialysis - Home (machine at home)	<input type="radio"/>				
Peritoneal Dialysis - Continuous Ambulatory (bag at home or any clean place)	<input type="radio"/>				
Peritoneal Dialysis - Automated (machine at home or any clean place)	<input type="radio"/>				



Use this space to write down any thoughts or questions you have about your choices to help the kidney health professionals plan your dialysis care:

(D) Further information

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11. Glossary

Below is a list of words health professionals use when talking about kidney disease and treatment options. Their meaning and abbreviation is given.

Term	Description of term	Abbreviation (where applicable)
Advanced kidney disease	See established kidney failure.	AKD
Arterio-venous fistula	See fistula.	AV fistula
Automated peritoneal dialysis	Dialysis that is usually carried out at night time for about 9 hours, automatically by a machine.	APD
Bacteraemia	A serious complication (sometimes called septicaemia), a blood stream infection, which can be treated with antibiotics, but in some cases can lead to serious additional problems can. Untreated bacteraemia can result in death.	
Catheter	A plastic tube called a catheter is put into the patient's abdomen so that peritoneal dialysis can take place.	
Chronic kidney disease	A long term condition where the kidneys do not work properly.	CKD
Chronic kidney failure	Another term for established kidney failure.	CKF
Chronic renal failure	Another term for chronic kidney disease.	
Chronic renal impairment	Another term for chronic kidney disease.	
Chronic renal insufficiency	Another term for chronic kidney disease.	
Conservative care	Supportive care for advanced chronic kidney disease that includes medications, diet but not dialysis.	
Continuous ambulatory peritoneal dialysis	Dialysis that is usually carried out about 4 times each day using bags of dialysate to perform an exchange.	CAPD
Creatinine	Creatinine is a waste product that is normally filtered out of the blood by the kidneys.	
Dialysate	Liquid used in dialysis, sometimes contains glucose.	
Dialysis	A treatment that can remove toxins and excess water from the body.	
End stage renal failure	Another term for established kidney failure.	ESRF
End stage renal disease	Another term for established kidney failure.	ESRD

Term	Description of term	Abbreviation (where applicable)
Encapsulating peritoneal sclerosis	A rare but particularly serious complication which causes damage to the peritoneal membrane. This damage makes people very unwell and can result in death.	EPS
Erythropoietin	A hormone (or a protein or a drug that helps the body make red blood cells to prevent anaemia.	EPO
Established kidney disease	The name of the condition when the kidneys stop working (or almost completely stop working).	EKD
Estimated Glomerular filtration rate	The eGFR shows how well kidneys filter fluid and clean the blood.	eGFR
(an) Exchange	The draining out of used liquid and the adding of fresh liquid in a peritoneal dialysis session.	
Fistula	A fistula is required for haemodialysis to take place. A surgeon joins a vein and artery together under the skin, usually in the forearm.	
Haemodialysis	Removes waste products and excess water from the patient's body using a machine.	HD
Home haemodialysis	Haemodialysis carried out in the patient's home.	HHD
Centre haemodialysis	Haemodialysis carried out in the hospital.	CHD
Nephrologist	A doctor who looks after people with kidney problems.	
PD tube	See Catheter.	
Peritoneal dialysis	Removes waste products and excess water from the patient's body using a salt based fluid that is added and removed from the patient's peritoneal space which lines the inside of the abdomen (belly) using a tube.	PD
Renal	Refers to anything to do with the kidneys.	
Kidney replacement therapy	A treatment that does some of the job of the kidneys.	KRT
Peritoneal (or Tenckhoff) catheter	See Catheter.	
Stage 5 CKD	Another term for established kidney failure.	
Transplantation	A surgical operation to add a kidney donated from another person.	
Uraemia	A condition where the body's waste products and excess water are not being removed from the blood.	

12. Further information for patients

Below are books and websites patients have found helpful when living with chronic kidney disease.

Books

Andy Stein and Janet Wild (2010). *Kidney failure explained* (4th ed.) Class Publishing, London.

Andy Stein and Janet Wild (2002). *Kidney dialysis and transplants. "At your fingertips" guide.* Class Publishing, London.

Patient Associations

British Kidney Patients association www.britishkidney-pa.co.uk

UK National Kidney Federation www.kidney.org.uk

Kidney information websites in the UK

Edinburgh Renal Unit www.edren.org

Kidney Dialysis Information Centre www.kidneydialysis.org.uk

Kidney Patient Guide www.kidneypatientguide.org.uk

Kidney Research UK www.kidneyresearchuk.org

NHS Chronic Kidney Disease www.nhs.uk/conditions/Kidney-disease-chronic

NHS Dialysis www.nhs.uk/conditions/dialysis

NHS Kidney care www.kidneycare.nhs.uk

NICE Guidelines www.nice.org.uk/guidance

The Renal Association www.renal.org

UK Renal Registry www.renalreg.com

Websites for carers (not specific to CKD)

www.carersweek.org

www.nhs.uk/Carersdirect/Pages/CarersDirectHome.aspx

13. Research used to write this Dialysis Decision Aid Booklet

Research-based publications: the facts in this booklet are informed by scientific papers from the following sources:

Referencing The Dialysis Decision Aid Booklet

- Bekker HL, Winterbottom A, Gavaruzzi T, Mooney A, Wilkie M, Davies S, Crane D, Tupling K, Mathers N of the Yorkshire Dialysis Decision Aid (YoDDA) Research Projects. The Dialysis Decision Aid Booklet: Making The Right Choices for You. Kidney Research UK: Peterborough, UK. (2014). www.kidneyresearchuk.org/health-information.

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Designing information to help people make treatment decisions

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- Gavaruzzi T, Summers B, Latchford G, et al. Is it better to present dialysis treatment choices in an option or attribute format? An experimental study. International Shared Decision Making Conference; Maastricht, NL, 19-22 June 2011.
- Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L, Wu JHC. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2014, Issue 1. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub4
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- The International Patient Decision Aid Standards (IPDAS) Collaboration's Quality Dimensions: Theoretical Rationales, Current Evidence, and Emerging Issues, *BMC Medical Informatics and Decision Making*, 2013, 13: S2. (<http://ipdas.ohri.ca/resources.html>) and Ottawa Hospital Research Institute – Patient Decision Aids (<https://decisionaid.ohri.ca/>)
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14. Thank you from the YoDDA research team

The YoDDA research team is grateful to all the patients and health professionals who took part in our studies and commented on drafts of this booklet. Their views and experiences helped make this booklet useful for people making these dialysis decisions.

The YoDDA research team members are:

- Patient Representatives: Dennis Crane (National Kidney Federation), Ken Tupling (Sheffield Kidney Patients Association).
- Health Professionals: Andrew Mooney, Gary Latchford (Leeds NHS Trust); Martin Wilkie, Lorraine Edwards (Sheffield NHS Trust); Simon Davies (University of Keele); Nigel Mathers (University of Sheffield).
- Decision Scientists: Hilary Bekker, Anna Winterbottom, Teresa Gavaruzzi, Barbara Summers (University of Leeds); Anne Stiggelbout (University of Leiden).
- Health Informatics: Susan Clamp (University of Leeds); Owen Johnson, Scott Jones (x-lab, University of Leeds).
- Health Services Research: Paul Baxter, David Meads (University of Leeds), Louese Dunn (Sheffield NHS Trust).

15. Patient information available from Kidney Research UK

Kidney Research UK is the largest charity dedicated to research into kidney disease in the UK, with the aim of finding better treatments, and ultimately cures for kidney diseases.

Our patient information resource service is freely available for kidney patients, their families and carers, as well as medical professionals and researchers, and provides advice and literature on how best to deal with each type of kidney condition, helping millions of people better understand the disease. Resources include:

Website

There is a wide range of downloadable resources available at the click of a button. Here you can find information on the treatment and management of kidney disease, FAQ's and blogs around patients living with kidney disease and much more. For more information and to browse what's available to you visit: www.kidneyresearchuk.org/health-information

Living with Kidney Disease DVD's

Kidney Research UK has a range of informative DVD's to order via our website. These DVDs provide vital information to patients and will help assist you in making the right choices about your lifestyle and, if necessary, treatment plans.

For more information visit: www.kidneyresearchuk.org/LivingwithKidneyDiseaseDVD

Dialysis Choices DVD

A new DVD is available to help people make a decision about which dialysis treatment fits best into their life. It provides an insight into every dialysis option currently available, told by six patients who have taken that particular route. Their stories give an idea of some of the practical realities and what it's like living with that choice on a day-to-day basis. For more information visit: www.kidneyresearchuk.org/DialysisChoicesDVD

Kidney care cookbook

This kidney care cookbook which was created by TV Chef Lawrence Keogh, Head Chef at Roast and BBC's Saturday Kitchen, along with Renal Dietician, Diane Green is now available free of charge to download via our website or from local Dieticians for patients who need to control their diet due to chronic kidney disease. The book which contains 16 recipes is called Rediscovering Food & Flavours. Visit: www.kidneyresearchuk.org/KidneyCareCookbook

For copies of the Kidney Research UK Dialysis Decision Aid, contact Kidney Research UK Health Information by:

Website: www.kidneyresearchuk.org/health-information

Email: kidneyhealth@kidneyresearchuk.org

Telephone: 0845 300 1499



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