



# 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 of 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. The studies were funded by Kidney Research UK in partnership with Baxter Healthcare Ltd and supported by the British Renal Society, Renal Association, The National Kidney Federation, The Informed Medical Decisions Foundation, USA, and Kidney Research Yorkshire.



Contact Professor Hilary Bekker ([h.i.bekker@leeds.ac.uk](mailto:h.i.bekker@leeds.ac.uk)) to find out more about patient decision aid research. The studies carried out to develop and update The Dialysis Decision Aid Booklet can be downloaded for free from:

Winterbottom AE, Gavaruzzi T, Mooney A, Wilkie M, Davies SJ, Crane D, Tupling K, Baxter PD, Meads DM, Mathers N, Bekker HL. Patient acceptability of the Yorkshire Dialysis Decision Aid (YoDDA) Booklet: a prospective non-randomised comparison study across 6 predialysis services. *Perit Dial Int.* 2016 Jul-Aug;36(4):374-81

Winterbottom AE, Bekker HL, Ziegler L, Hipkiss V, Williams R, Russon L, Mooney A. The Yorkshire Dialysis vs Conservative-management Decision Aid (YoDCA): study protocol. *Journal of Kidney Care.* 2018; 2: 179-185 ([doi.org/10.12968/jokc.2018.3.3.179](https://doi.org/10.12968/jokc.2018.3.3.179))

Winterbottom AE, Mooney A, Russon L, Hipkiss V, Ziegler L, Williams R, Finderup J, Bekker HL. Kidney Disease Pathways, Options and Decisions (KD-POD): An Environmental Scan of International Patient Decision Aids (PtDA). *Nephrol Dial Transplant* (2020) 1–11. [10.1093/ndt/gfaa102](https://doi.org/10.1093/ndt/gfaa102).

Winterbottom AE, Mooney A, Russon L, Hipkiss V, Ziegler L, Williams R, Bekker HL. Critical review of leaflets about conservative management used in UK renal services. *Journal of Renal Care* (2020). [10.1111/jorc.12327](https://doi.org/10.1111/jorc.12327)

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.

# Endorsements

The Dialysis Decision Aid Booklet accurately reflects recommendations in the [NICE guidance on renal replacement therapy and conservative management](#) (NG107, 2019). The National Institute of Health and Care Excellence Endorsement Statement, April 2020.

The Dialysis Decision Aid Booklet is recommended by patient and health professional organisations in the UK and internationally - highly commended by KidneyCare UK (2020) and the British Medical Association Patient Information Awards (2014), endorsed for use in dialysis education programmes by the European Renal Best Practice committee and International Society of Peritoneal Dialysis, and approved by the international Decision Aid Library Inventory system (<https://decisionaid.ohri.ca/AZinvent.php>).



## Referencing this 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) Team. The Dialysis Decision Aid Booklet: Making The Right Choices for You. Kidney Research UK: Peterborough, UK. (2020).  
Date of next content review and update, January 2023.

[www.kidneyresearchuk.org/DialysisDecisionAid](http://www.kidneyresearchuk.org/DialysisDecisionAid)

## For copies of the Kidney Research UK Dialysis Decision Aid booklet, contact Kidney Research UK by:

- Website: [www.kidneyresearchuk.org/health-information/resources](http://www.kidneyresearchuk.org/health-information/resources)
- Email: [kidneyhealth@kidneyresearchuk.org](mailto:kidneyhealth@kidneyresearchuk.org)
- Telephone: 0300 303 1100

Hard copies of the Dialysis Decision Aid are available to post to UK addresses only and are available to order in bulk by UK renal units, paying only the cost of postage and packing. Kidney Research UK encourages widespread use of this Dialysis Decision Aid Booklet, including in territories outside the UK. Quanta Dialysis Technologies funded printing of the Dialysis Decision Aid Booklet 2020. No adaptations other than language translation are permitted.

If you wish to undertake a research or quality improvement project using the Dialysis Decision Aid booklet contact the charity and Professor Bekker about collaboration.

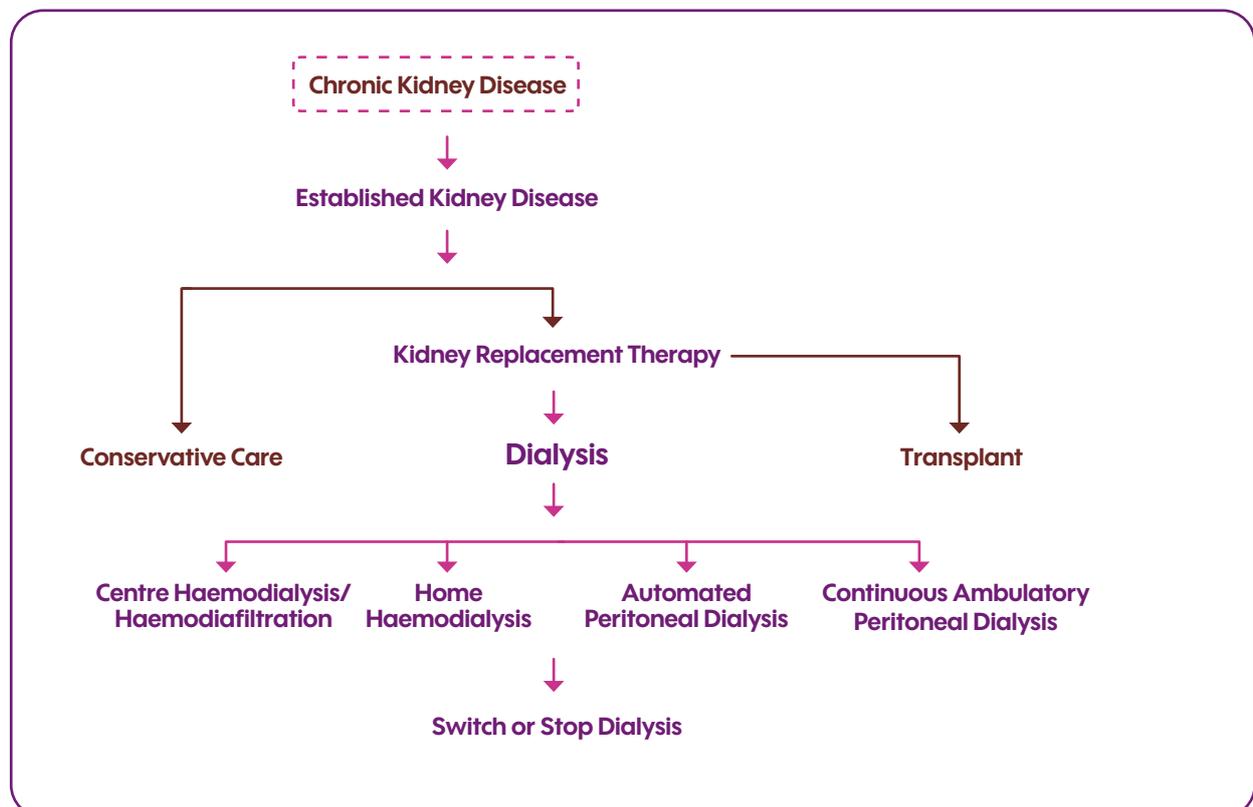
# Using this Dialysis Decision Aid booklet

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 with chronic kidney disease link the information in the booklet with the decisions they are making. The maps signpost the next topic in the booklet. For example, the map below has a dotted box around chronic kidney disease. The first topic in the booklet is about chronic kidney disease.
- **Content pages** lists 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).

<b>(A) Information about chronic kidney disease</b>	
1. What is chronic kidney disease?	08
2. What is progressive chronic kidney disease?	11
3. What is established kidney disease?	13
4. Treatment choices for established kidney disease	16
<b>(B) Information about dialysis options</b>	
5. Introduction to dialysis treatments	20
6. Thinking about the dialysis decisions	23
7. Common features of dialysis	26
8. Differences between dialysis treatments	30
<b>(C) Making the dialysis decision</b>	
9. Comparing all four dialysis treatments	36
10. Making the dialysis decision	38
<b>(D) Further information</b>	
11. Glossary	42
12. Further information and patient resources	44
13. Research and policy papers used for The Dialysis Decision Aid Booklet	45
14. Patient information available from Kidney Research UK	47
15. Thank you from the YoDDA & YoDCA research team	48

# **(A) Information about chronic kidney disease**

1. What is chronic kidney disease?	08
2. What is progressive chronic kidney disease?	11
3. What is established kidney disease?	13
4. Treatment choices for established kidney disease	16

# 1. What is chronic kidney disease?

**Chronic kidney disease (CKD)** is a long-term health problem where the kidneys slowly stop working. About six-eight people out of every 100 (6-8%) in the UK have kidney function which is described as moderately or severely reduced (see page 12). Over time, the damaged kidneys may 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?

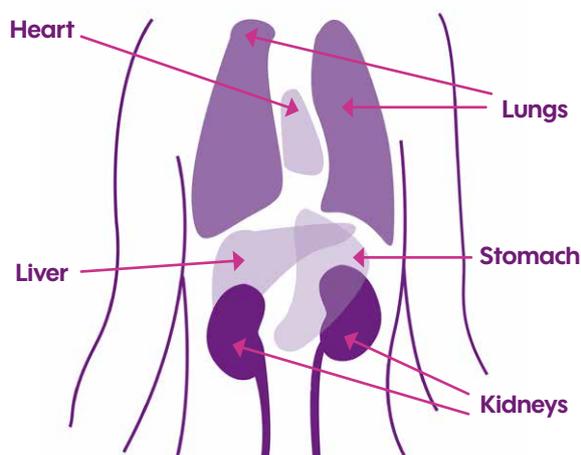
When the kidneys are damaged permanently they cannot do their usual jobs. As a result, harmful toxins and excess fluid build up in the body. Kidneys do five types of jobs for our bodies:

- 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.

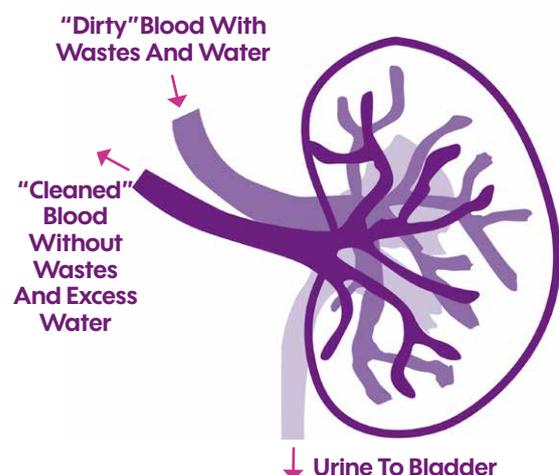
## Where are the kidneys?

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).

**Picture 1:**  
Where the kidneys are in the body



**Picture 2:**  
The kidney and how it works



### What causes chronic kidney disease?

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 some painkillers and 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:

- Specialist Kidney Nurses provide advice about fitting medications, dialysis, advance care plans, and other treatments into people's daily life to manage their established kidney disease.
- Specialist Kidney Dieticians provide advice on lifestyle, food, fluids and nutrition to keep kidneys as healthy as possible, and manage kidney disease symptoms.
- 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.

### **Coping with chronic kidney disease**

People with chronic kidney disease (CKD) can lead full lives but they often need to make changes to manage their disease. Many people with CKD need help from other people, especially if the disease gets worse. This help can come from their family, friends and/or health professionals.

People choose to cope with their illness in different ways. Being active in choosing treatments and in managing the illness helps maintain a feeling of being in control and helps people make sure they get the treatment that best suits their lives. People with CKD who become more involved in the management of their care have better health outcomes.

It is common for patients to become experts on how to manage their kidney disease. To live as normal a life as possible, patients with kidney disease take medication and control the food and water they have every day, for the rest of their lives (pages 29-30).

Section 12 has more information for people with CKD, and their friends and family.

**Use the space below to jot down notes or questions you have about your experience of chronic kidney disease:**



## 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.

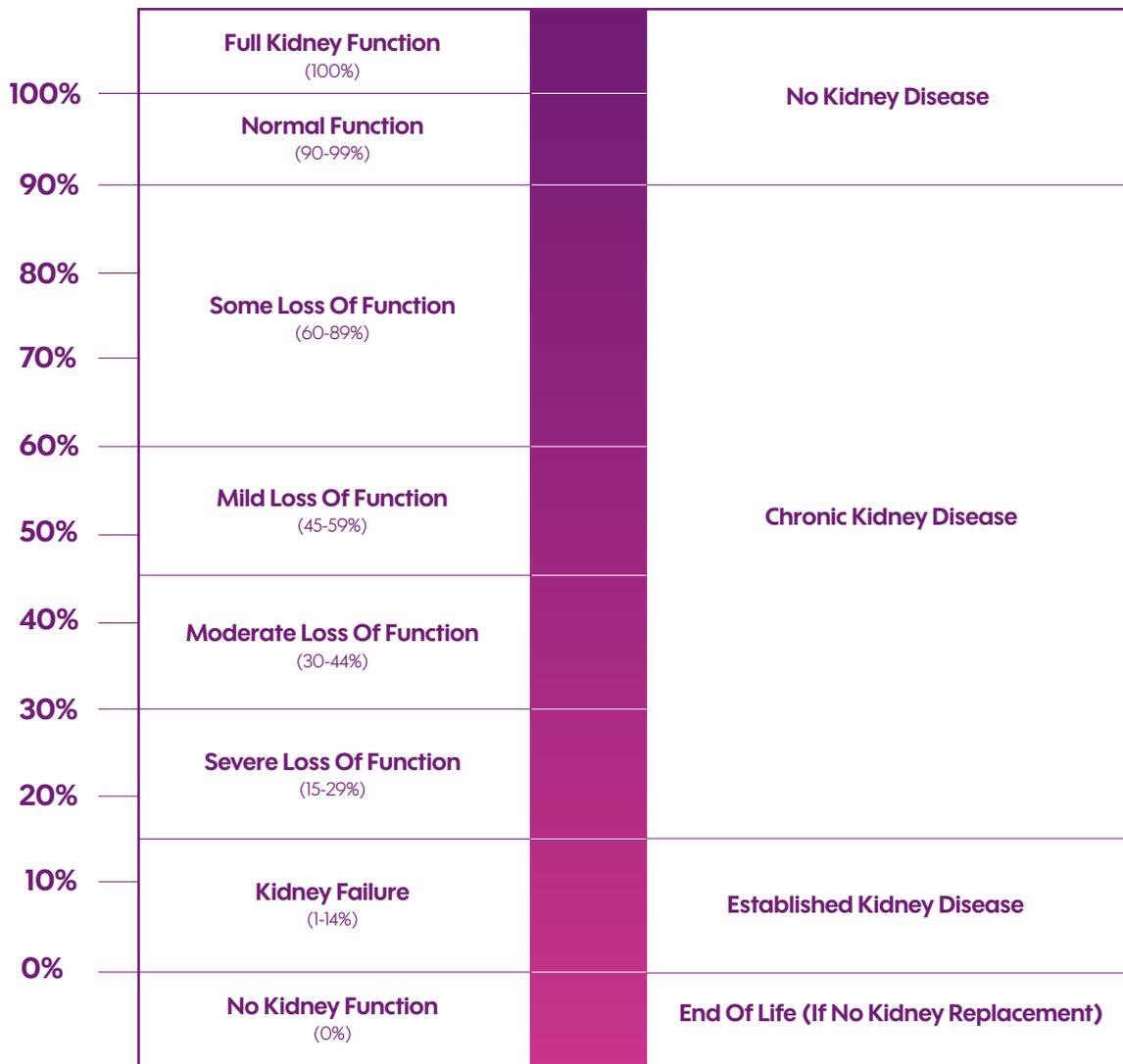
### Tests checking how well people's kidneys are working

The results of two tests are used to check the kidneys, and work out how well they are functioning:

- Estimated Glomerular Filtration Rate (eGFR) is a blood test which checks how well the kidneys work to filter out waste from a person's blood. Normally the kidneys filter 100 ml of blood every minute. The loss of kidney function in people with kidney disease means less than 100 ml of blood every minute will be cleaned and the eGFR result starts to fall.
- Albumin to Creatinine Ratio (ACR) is a urine test and checks how well the kidneys work to keep proteins in a person's blood. Normally there is a tiny amount of Albumin (result 0-2 mg/mmol) found in a person's urine. The loss of kidney function in people with kidney disease means 3 mg/mmol or more of Albumin is found in a person's urine and the ACR result starts to rise.

Some people find it useful to think of kidney function as a percentage, going from 100% (fully functioning) to 0% (no function). Section 13 lists research and guidance papers used to find facts about chronic and established kidney disease and its treatment [numbers 1-19 (see picture 3)]. If a person's kidney function starts falling, there is a chance the kidney disease is getting worse. As kidney disease gets worse, people need different treatments to manage symptoms and do the work of the kidneys.

**Picture 3: Linking Loss of Kidney Function with Worsening Kidney Disease**

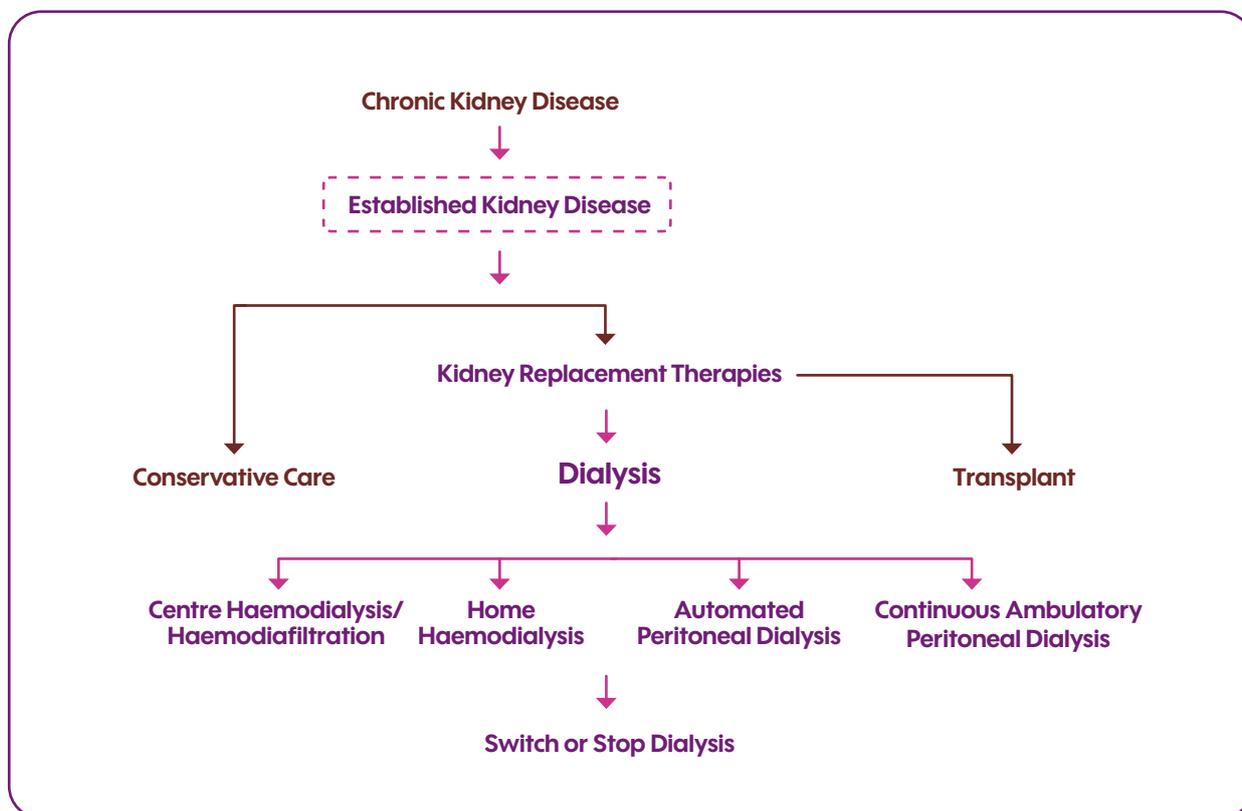


Use the space below to note any questions you have or ask others to write down information:



# 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 advanced kidney disease (AKD), stage 5 CKD, grade 5 classification CKD, end stage renal failure 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

Kidney professionals monitor people with established kidney failure to plan care together that protects their kidneys and slows down damage to the body from losing their kidney function, keeps people as well as possible, and manages symptoms of worsening kidney disease. Some of the common problems that can cause symptoms for people with EKD 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 that 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

**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.

**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.

### **Getting used to established kidney disease**

When people are told their kidneys are failing, it affects their lives and how they feel, and how their friends and family 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.

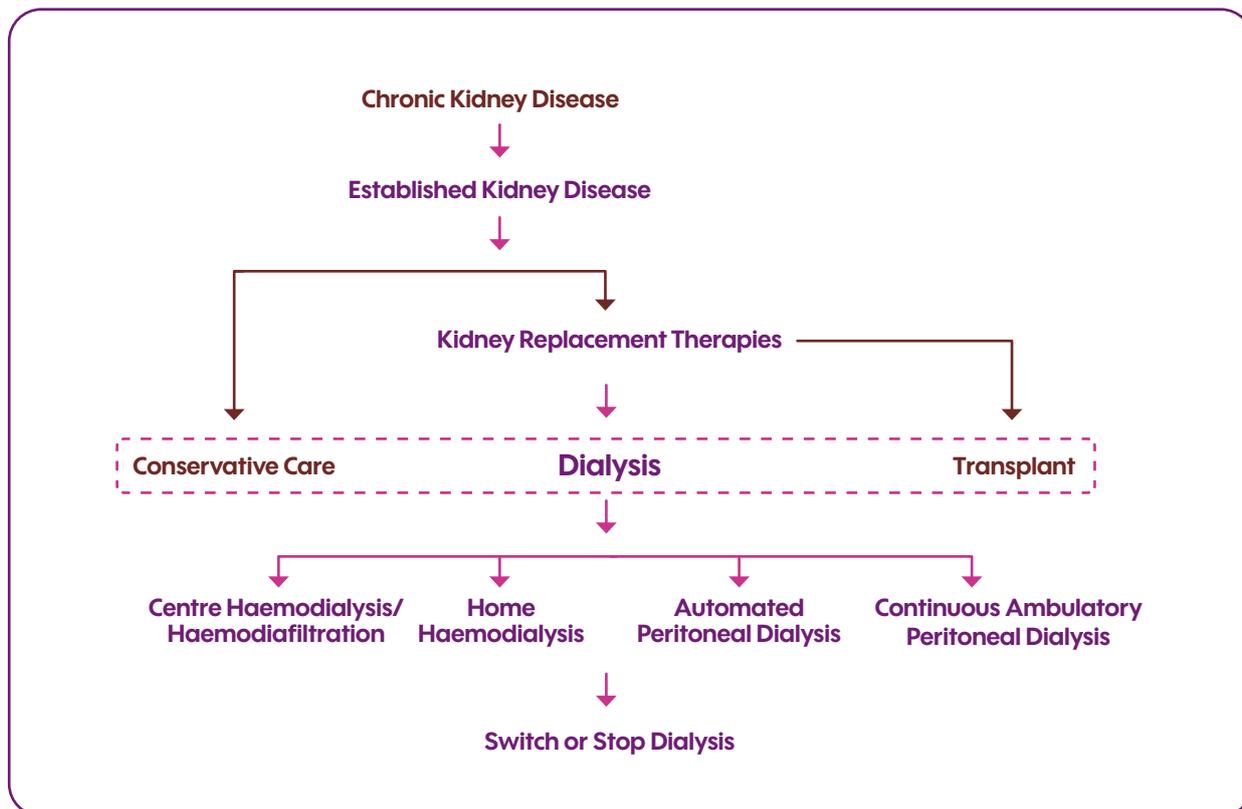
People find that knowing more about kidney failure and the treatments available helps them cope with it better. Some people find sharing their experiences and feelings with other patients, and friends and family, can help. Different kidney services offer different types of care to support people coping with their kidney disease.

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, dialysis and transplant pathways



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).

**Conservative care** uses medicines, diet and fluid therapies, lifestyle advice, and other treatments to keep people as healthy as possible, and manage symptoms. Conservative care follows a similar routine to chronic kidney disease care, with people adding extra treatments to cope with symptoms as their kidney disease worsens. People's length of life depends on the speed of their kidney failure, age, ability to do daily activities, and other health problems.

**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.

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

Dialysis lengthens life in people who are generally fit and well. It might not lengthen life for people who are older, have other long-term illnesses and have difficulty looking after themselves. For some people they are deciding between adding a conservative care or dialysis treatment routine to their kidney disease management. The Dialysis and Conservative Care Decision Aid Booklet helps people think about what is important to them about these treatment pathways ([www.kidneyresearchyorkshire.org.uk/home/yodca/](http://www.kidneyresearchyorkshire.org.uk/home/yodca/)).

The rest of this Dialysis Decision Aid Booklet is for people who think it is worth adding a dialysis routine into their daily life to manage their kidney disease and symptoms.

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 is 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.



**Kidney transplant** is when a kidney is taken from a person without kidney disease (donor) and put inside the body of a person with kidney disease (recipient). Kidney transplant operations are done by surgeons. The transplanted kidney is put near to the kidneys in the body of the person with EKD. Not everyone with kidney disease can have a kidney transplant. As people get older, or get other health problems, they are less likely to be able to have a transplant 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. Transplanted kidneys do the jobs needed to keep the body healthy. They do enough work to mean people do not have to restrict their diet and fluid in the same ways as before the operation. Most people who have transplants have a better quality of life and survival rate than those on dialysis.

Some people with kidney disease put their names on a transplant waiting list. These people are given a kidney from a person who has died: a deceased donor - after brain death (DBD) or after cardiac death (DCD). People wait for a kidney to be donated that matches their blood and tissue type. On average, people on the kidney waiting list wait for 2-3 years. Many people with kidney disease decide which type of dialysis to have while on the transplant waiting list. About 70% of people are on dialysis at the time they have a transplant.

Some people are given a kidney from a person who is alive: a living kidney donor (LKD). Some people know the person, often a family member or friend, who donates the kidney, a directed donor. Some people do not know the person donating the kidney: a non-directed or altruistic donor. LKD begins as soon as the donor's and recipient's kidneys are matched, and both people are ready to have the operations.

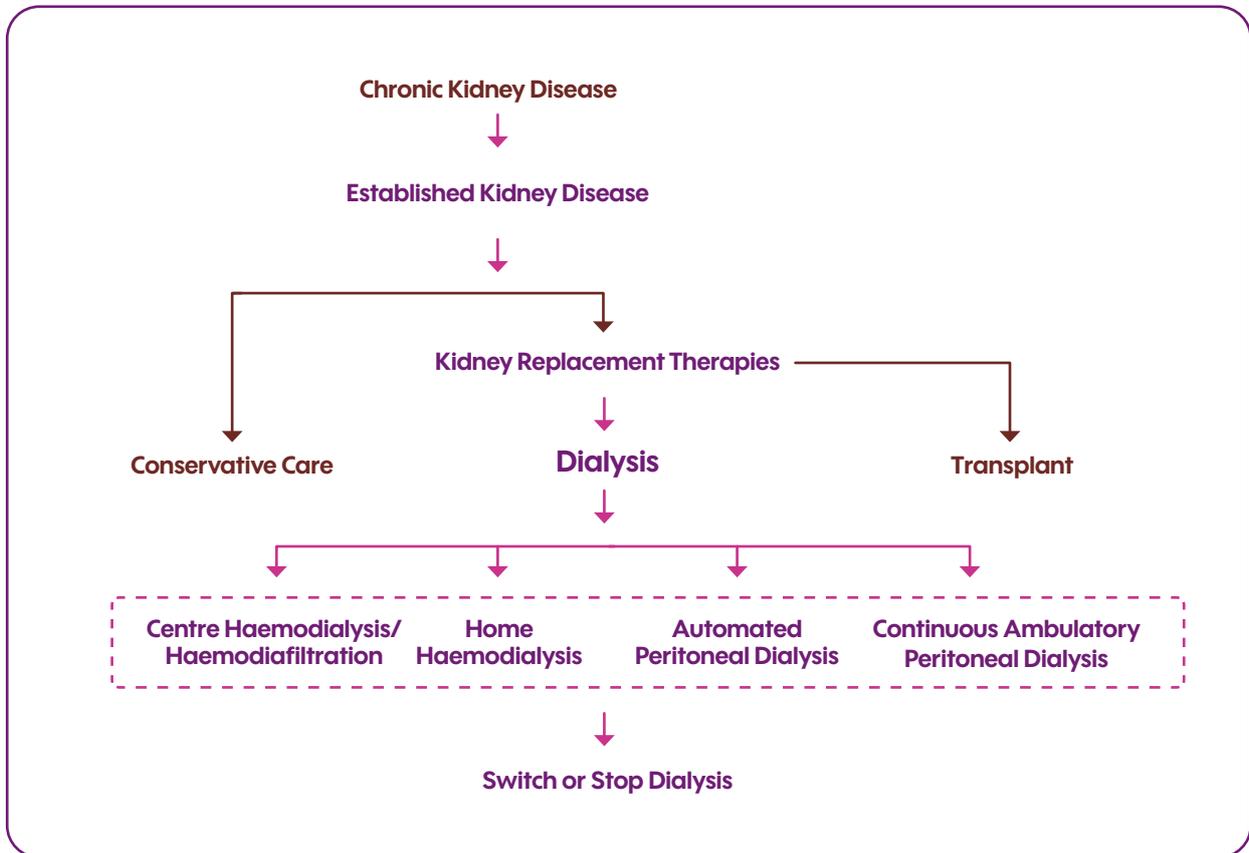
Most transplanted kidneys start to work a few days after the operation. After 1 year about 94% (94 out of 100) of people with a DCD kidney have a functioning kidney, and about 98% (98 out of 100) of people with a LKD have a functioning kidney. Over time, the transplanted kidney can begin to lose its function. On average, transplants from deceased donors last around 10-12 years and those from living donors last around 12-15 years. People whose transplanted kidney starts to fail make decisions about kidney transplant, dialysis and conservative care.

# **(B) Information about dialysis options**

5. Introduction to dialysis treatments	20
6. Thinking about the dialysis decisions	23
7. Common features of dialysis	26
8. Differences between dialysis treatments	30

# 5. Introduction to dialysis treatments

## Decision map 4 - Dialysis treatments



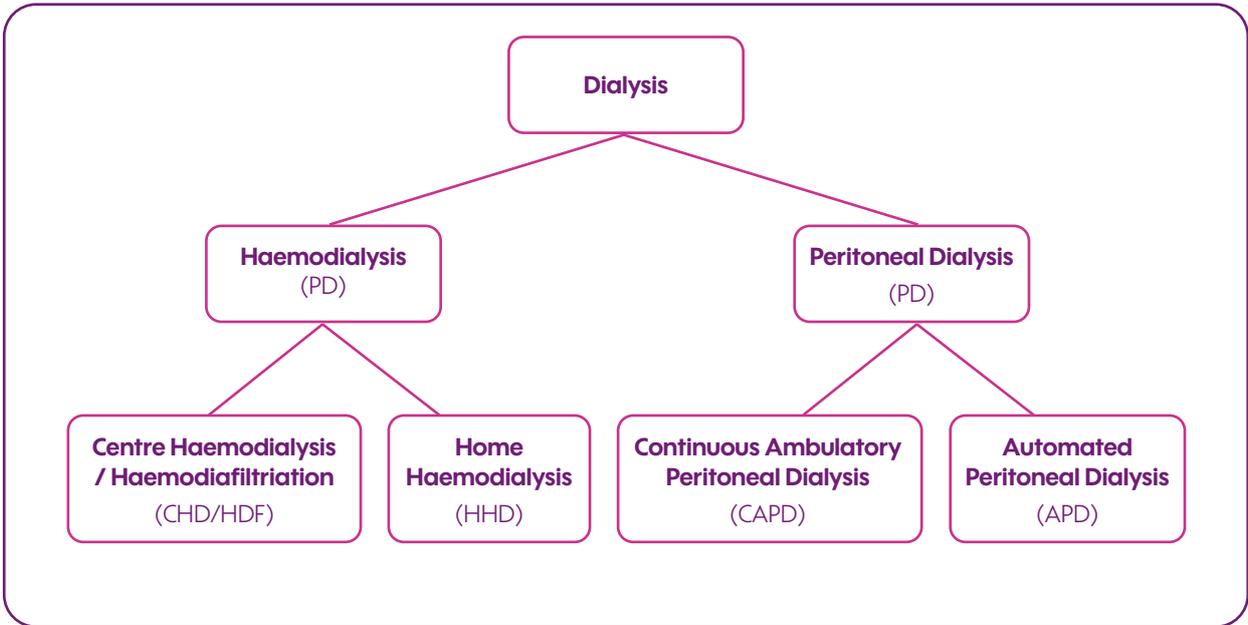
The booklet describes four dialysis treatments. For most people, each dialysis treatment works as well as each other to remove toxins and fluids from people's bodies. There are advantages and disadvantages to all dialysis options. Each person's life is different, so people need to think about which treatment option suits their life best. Some people say it is useful to read about all four options before making a decision. Some people find 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 the 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 with EKD make a decision between two types of dialysis to take away the toxins, waste and excess fluid from their bodies:

**Haemodialysis (HD)** uses a machine outside the body to pump blood out, clean it, pump the cleaned blood back in, and throw away the waste products. People have an access point (fistula) made in an arm or leg to let the blood be pumped out, and back in. A surgeon joins an artery with veins under the skin to make the fistula for people to use for all their dialysis sessions. The dialysis machine has man-made membranes to keep the blood, dialysis fluid (dialysate) and water separate, and to filter the waste products out of the blood. The different types of dialysis machines are, Haemodialysis (HD) and Haemodiafiltration (HDF).

**Peritoneal dialysis (PD)** uses the body’s filtering processes to clean a person’s blood as it moves naturally around the internal organs and intestine. People have an access point made in their belly by a surgeon who fits in a soft tube (catheter) to let dialysis fluid (dialysate) be drained in and out of the body. Inside people’s belly is the peritoneum membrane covering the internal organs and intestine. It makes a space between the internal organs and belly-wall known as the peritoneum cavity. Fresh dialysis liquid (dialysate) is drained into this space. The peritoneum membrane lets waste products filter into this fluid from people’s blood as it moves around the internal organs. The used dialysate is drained out and waste products thrown away, and fresh dialysate added. The different types of peritoneal processes are Continuous Ambulatory Peritoneal Dialysis (CAPD) and Automated Peritoneal Dialysis (APD).

Kidney services work with people with EKD to decide which dialysis type fits best into their lives. Most kidney services can support people to have dialysis at home (CAPD, APD, HHD) or at a kidney centre (CHD, HDF). Most services can organise a health professional to help people carry out dialysis at home if they need extra support with everyday tasks (Assisted Dialysis).

The rest of this booklet has information and prompts to help you think about what is important to you about these dialysis treatments. People find thinking about this information helps them to prepare and talk with their kidney team and family about why, and how, one type of dialysis treatment fits better into their life than another.

For most people each treatment is equally good at removing waste products from the body. Ask your kidney doctor if there is something about your health that means one type of dialysis option is medically better for you than another. The dialysis treatment differ in the following ways (see summary table pages 36-37):

- 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.

## 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 professionals meet with people making dialysis, and their families, to help find a dialysis treatment that fits best into their daily life and manage any other health problems.

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 kidneys 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 over with family and friends 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. In some centres, staff and patients work together to create and develop opportunities for patients to learn how to take on aspects of their own haemodialysis care - this is known as Shared Haemodialysis Care.

### Other patients' experiences of dialysis

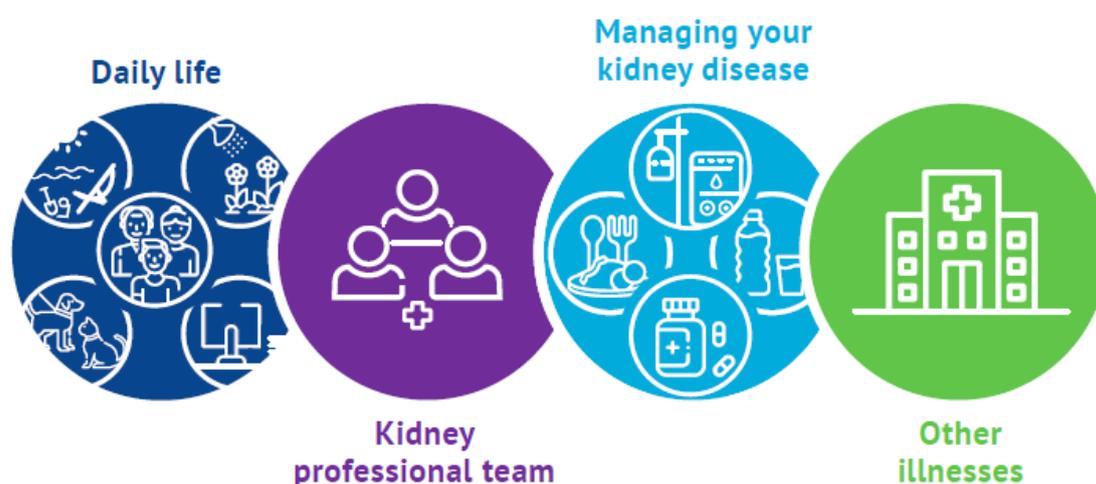
Some people find it useful to hear other patients' stories of living with dialysis. Some people talk to patients about their kidney disease whilst waiting for their appointments during routine hospital visits. Although others' experiences of dialysis and established kidney disease can help people live 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 dialysis routines

After people start dialysis, they often make adjustments or changes to their treatment. Kidney professionals work with patients to change their dialysis routines to help fit them into their lives. Sometimes people decide to change the type of dialysis they chose. People make these change for two reasons:

- A person's kidney disease and health change over time. For example, some people's kidney disease gets worse, they get another health problem, or there is a complication with the dialysis they chose.
- 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 their home with them.



Section 13 lists research and guidance papers used to find out the facts about EKD and dialysis options that people need to think about when deciding which option fits best into their daily life (see pages 45-46).

**Use this section to note down anything that is important in your life to help your talking about which dialysis option will fit best in your life to manage your kidney disease:**



## 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 professionals when they go to hospital for their kidney disease check-ups. People on dialysis will also regularly see the specialist dialysis team to check on how well their dialysis is working for them. The dialysis professionals have experience 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 their body, 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. People will need an anaesthetic when these access points are made. Surgery and an anaesthetic 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 professionals help people learn how to carry out dialysis safely and keep the access point clean. If bacteria get into the access point, they 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

These are types of dialysis-related side-effects that are unpleasant, can be serious, and may need treatment:

- Infection which happens when bacteria gets into the body through the access point. 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 diet and the amount of liquid people can have

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.

Most people are asked to change their food and drink when they start dialysis. The kidneys help the body take out the right amount of energy and goodness from the food and drink people have. Kidney disease means the body does not get the right balance of liquids and goodness to work well. Specialist kidney dietitians talk with people to find the best diet for their kidney health, taking into account people's weight, body size, other illnesses, lifestyle, religion and culture, and type of dialysis they have.

The kidney dietitian helps people think through which types of food and drink they want to 'trade-off' to find changes to fit best into their daily life. It can be challenging to make these changes. Most people need to drink less than a litre (2 pints) a day, avoid eating foods with a high fluid content like ice cream, sauces, and soup. Most people are asked to reduce eating foods with that have a lot of sodium, potassium or phosphate, such as:

- Foods high in sodium - ready-to-eat-meals and sandwiches, bacon and ham, smoked fish, cheese, adding extra salt to meals.
- Foods high in potassium - bananas, baked potatoes, oranges, chocolate.
- Foods high in phosphate - dairy products like cheese and yogurt, baked beans, lentils, sardines, bran cereals.

## Changes to medicines and vitamins

These changes are worked out with the kidney dietician and the kidney team. 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.

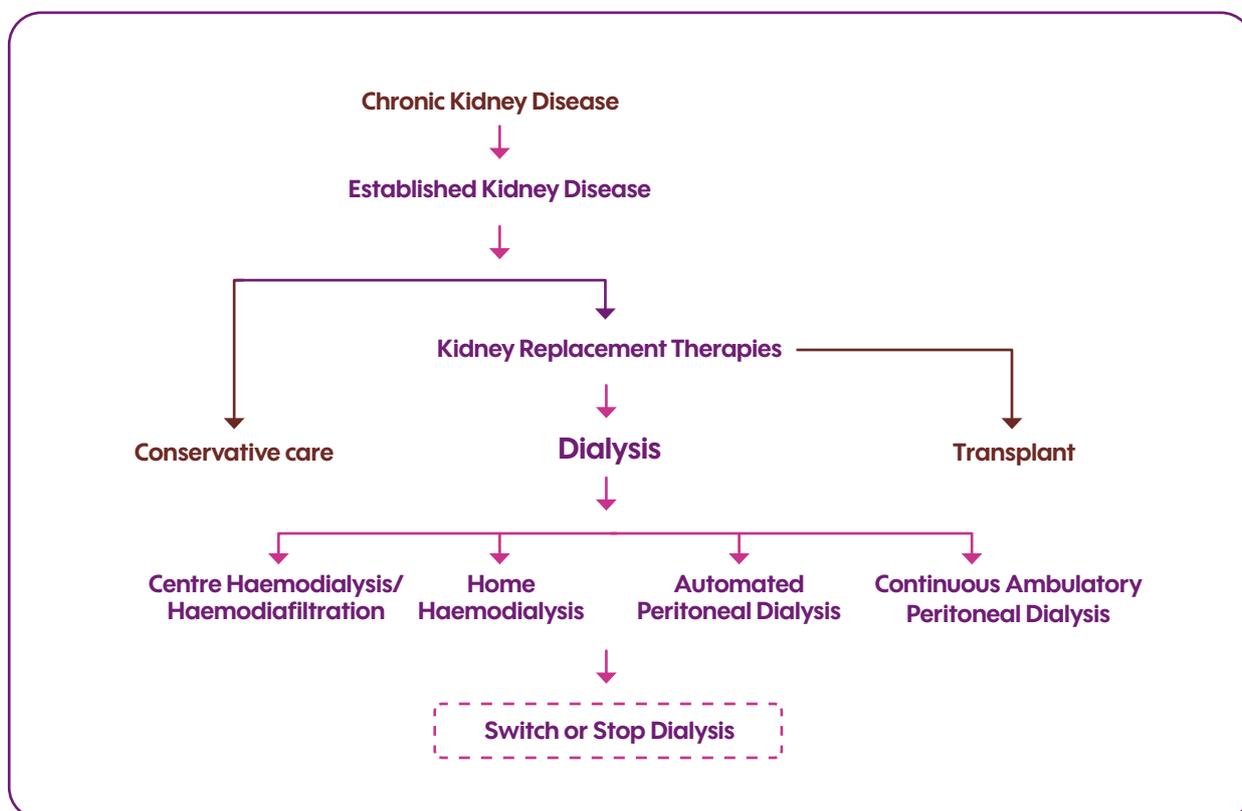
## Switch or stop dialysis

Over time people on dialysis may feel more unwell and have more symptoms as their EKD worsens. Kidney professionals work with people to adjust their dialysis routines, and diet, lifestyle and medication therapies to manage symptoms. Some people may switch to another type of dialysis to fit better with their medical problems or personal life (see page 26)

When people's EKD worsens, they can get more symptoms. People may no longer enjoy their hobbies or plan social and healthcare activities in the way they used to. Making **Advance Care Plans** (ACP) with family and kidney professionals about what treatments to change, start or stop, when they still feel well can help people lead a good quality life for as long as possible. When these changes to people's health happen, kidney professionals offer treatments to relieve people's symptoms and give some comfort. These types of options are sometimes known as **palliative care**.

For some people, they can feel their dialysis no longer helps them manage their kidney failure, and they want to stop fitting a dialysis routine into their daily life. Kidney professionals help people stop their dialysis treatments, and plan care as they move towards End of Life (EoL). Trained nurses and doctors help manage the symptoms people experience when they stop dialysis and have no kidney function left. This stage of EKD management is known as **End of Life** (EoL) care.

## Decision map 5 - Switching and stopping dialysis as EKD worsens



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



# 8. Differences between dialysis treatments

This table has facts about haemodialysis and peritoneal dialysis. People find it useful to understand why these dialysis methods are different. Page 40 has a summary of all four dialysis types: CHD/HDF, HHD, CAPD, APD.

	<b>Haemodialysis (HD)</b>	<b>Peritoneal Dialysis (PD)</b>
<b>The Different Names</b>	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.
<b>How Dialysis Works</b>	<p>HD works by using a machine to pump blood from a person's body to a machine, and back again. Blood is pumped in and out of the machine quickly, and at the same time, so that people do not experience blood loss or too much change in blood pressure. The blood is pumped through the machine several times.</p> <p>The machine has several parts allowing the blood to be cleaned using dialysis fluid (dialysate) and water. Membranes separate the blood from these liquids. Membranes filter out waste products and extra fluids from the blood. This used dialysate is pumped out and thrown away. The cleaned blood is pumped back into the body. Haemodialysis (HD) and Haemodiafiltration (HDF) machines use different processes to filter out the waste products from the blood.</p>	<p>PD works by using natural processes inside the body to filter out waste products from the blood as it moves around the internal organs and intestine. The membrane called the peritoneum separates people's internal organs and intestines from a space in the body known as the peritoneum cavity. The peritoneum acts as a filter when a dialysis fluid (dialysate) is added to the peritoneum cavity.</p> <p>The peritoneum lets waste products and excess water be drawn out of a person's blood into the dialysis fluid. This filtering process is known as diffusion. After at least 1 or 2 hours the used dialysis fluid is drained out into a bag, and thrown away; a fresh bag of dialysis fluid (dialysate) is drained into the peritoneum cavity or space. A person's blood keeps moving around the body naturally</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 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 (8 inches) 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 HD/HDF session takes about four hours to remove all the waste products from the blood. The machine is fixed to a person's arm or leg using their fistula. Needles are used to let the blood be pumped out of (arterial) and pumped back into (venous) the body. People use a plaster at the end of the session, when the needles are taken out.

People have at least three HD/HDF sessions per week, each lasting 4 hours. People can have HD at home (HHD) or at a centre (CHD), and HDF at a centre. People having CHD or HDF need to add travel times to, and from, the centre when planning their dialysis sessions.

### Peritoneal Dialysis (PD)

A PD session drains, and adds, dialysate fluid to a person's belly through a catheter. The used dialysate in the belly is drained out into one bag, and fresh fluid added from another bag. This process is called an exchange. The dialysis fluid stays in the belly between sessions. People put a cap on the catheter at the end of the session.

For CAPD (continuous ambulatory PD), a bag is used for the session. The session has one exchange lasting for about 45 minutes in any clean place they feel comfortable. People usually fit four CAPD sessions into a day, two in the morning, one in the afternoon and one in the evening.

For APD (automated PD), a machine is used to allow several exchanges to happen in one session lasting about nine hours. People usually have one APD session every night at home, while they sleep.

---

## 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.

## Haemodialysis (HD)

### Dialysis-related Complications

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. 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 cough. Surgery is usually needed to fix a hernia.

## Haemodialysis (HD)

### Dialysis-related illnesses

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.

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.

## 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.

Some people may get Encapsulating Peritoneal Sclerosis (EPS). EPS means the lining of the stomach (peritoneum membrane) gets thicker and hardens (sclerosis) as it is coated in calcium (encapsulated). People with EPS may get bowel blockages and symptoms such as pain, weight loss, and nausea. The treatment usually includes surgery and steroids. There is a chance people will die when they are treated for this damage..

# **(C) Making the dialysis decision**

9. Comparing all four dialysis treatments	36
10. Making the dialysis decision	38

## 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)	
	CHD/ HDF: Centre Haemodialysis / Haemo- diafiltration	HHD: Home Haemodialysis	CAPD: Continuous Ambulatory Peritoneal Dialysis	APD: Automated Peritoneal Dialysis
<b>Place Of Dialysis Care</b>	People travel to kidney centres for CHD/ HDF sessions	People have CHD sessions at home	Most people choose to have CAPD at home or work, Can be any clean place	Most people choose to have APD at home, Can be any clean place
<b>How Dialysis Works</b>	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 45 minutes by the belly	Attaching to a machine for about 9 hours by the belly
<b>Usual Number Of Sessions In A Week</b>	3 times a week (day)	At least 3 times a week (day or night)	Every day	Every night
<b>Usual Number Of Sessions In A Day</b>	1 x 4 hour session	1 x 4 hour session	4 x 45 minute sessions	1 * 9 hour session
<b>People Carrying Out Dialysis</b>	Staff at the centre. Person with EKD trained for shared care.	Person with EKD trained by kidney staff.	Person with EKD trained by kidney staff.	Person with EKD trained by kidney staff.
<b>Assisted and shared dialysis</b>	Some people are trained to share CHD/HDF care in centres.	A carer can be trained to carry out HHD. A carer can be family, friend or health assistant (assisted HHD).	A carer can be trained to carry out CAPD. A carer can be family, friend or health assistant (assisted CAPD).	A carer can be trained to carry out APD. A carer can be family, friend or health assistant (assisted APD).

	<b>Haemodialysis (HD)</b>		<b>Peritoneal Dialysis (PD)</b>	
	<b>CHD/ HDF: Centre Haemodialysis / Haemo- diafiltration</b>	<b>HHD: Home Haemodialysis</b>	<b>CAPD: Continuous Ambulatory Peritoneal Dialysis</b>	<b>APD: Automated Peritoneal Dialysis</b>
<b>Usual Time Of Dialysis</b>	Most sessions happen during the day. People sit or lie on a couch or bed to read, sleep, or watch TV.	Most people choose day time. People sit or lie on a couch or bed to read, sleep, or watch TV.	Most people choose times: in the morning, and before lunch, the evening meal and bedtime. Most people sit or stand during exchanges.	Most people choose night-time. Most people are asleep
<b>Equipment Needed</b>	A machine outside the body, plumbed in, next to a bed or chair at the centre. Machine about the size of a washing machine.	A machine outside the body, plumbed in, next to a bed at home. Machine about the size of a washing machine, and dialysate fluid.	A hook to hang the bag of fluid during the exchange. Bags of clean fluid and bags to take away used fluid (dialysate).	A machine outside the body, about the size of a small suitcase. Bags of clean fluid and bags to take away used fluid (dialysate)
<b>Changes ToThe Home</b>	None, carried out at kidney centre.	The machine plumbed into a person home. Storage needed for the machine and reclining chair or bed, and supplies	Storage is needed to keep bags of dialysate fluid, like a cupboard or clean space in a shed, basement or garage.	Storage is needed to keep bags of dialysate fluid, like a cupboard or clean space in a shed, basement or garage.
<b>Kidney Service Support For dialysis</b>	Services organise transport to help people get to kidney centres They help plan trips away from home.	Services organise the machine delivery, change to the home and help plan other dialysis options when people have trips away from home.	Services organise equipment and deliveries for home. They help plan dialysis for trips away from home.	Services organise equipment and deliveries for home. They help plan dialysis for 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?



Tick one circle for each treatment.

**Not at all**

**No Maybe**

**Unsure**

**Yes Maybe**

**Yes Definitely**

**PD Continuous Ambulatory**






**PD Automated**






**Home HD**






**Centre HD/HDF**

**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**

**PD Continuous Ambulatory**






**PD Automated**






**Home HD**






**Centre HD/HDF**






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**

11. Glossary	42
12. Further information and patient resources	44
13. Research and policy papers used for The Dialysis Decision Aid Booklet	45
14. Patient information available from Kidney Research UK	47
15. Thank you from the YoDDA & YoDCA research team	48

# 11. Glossary

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

<b>Term</b>	<b>Description of term</b>
<b>Advance Care Plan</b> (ACP)	A written statement about a person's wishes, values and choices about future care. Made with health professionals and anyone else who might make decisions about a person's care if if they are not able to tell someone what they want.
<b>Arterio-venous fistula</b> (AV fistula)	See fistula.
<b>Bacteraemia</b> <b>septicaemia</b>	A serious infection in the blood stream which can be treated with antibiotics. In some cases it can lead to other serious problems, and may result in death.
<b>Catheter</b>	A soft plastic tube used to make the access point for peritoneal dialysis.
<b>Chronic Kidney Disease,</b> <b>Kidney Failure,</b> <b>Renal Failure,</b> <b>Renal Impairment</b>	All terms for a long-term condition where the kidneys do not work properly.
<b>Conservative care</b> (CC)	A treatment plan to keep the kidneys as healthy as possible and manage the symptoms of kidney failure using medicines, diet and fluid therapies, lifestyle advice, and other treatments.
<b>Continuous Ambulatory Peritoneal Dialysis</b> (CAPD)	Dialysis that is usually carried out about 4 times each day using bags of dialysate to perform an exchange.
<b>Creatinine</b>	Creatinine is a waste product that is normally filtered out of the blood by the kidneys.
<b>Dialysate</b>	Liquid used in dialysis, sometimes contains glucose.
<b>Dialysis</b>	A treatment that can remove toxins and excess water from the body.
<b>Encapsulating Peritoneal Dialysis</b> (EPS)	A problem a few people on PD get that means their peritoneum membrane is coated with calcium, causing bowel blockages, making people ill and needing surgery.
<b>Erythropoietin</b> (EPO)	A hormone (or a protein or a drug) that helps the body make red blood cells to prevent anaemia.

<b>Term</b>	<b>Description of term</b>
<b>Established Kidney Disease, Established Kidney Failure, End Stage Renal Disease, End Stage Renal Failure (EKD)</b>	Names given to the condition when the kidneys stop working, or almost completely stop working.
<b>Estimated Glomerular filtration rate (eGFR)</b>	The eGFR shows how well kidneys filter fluid and clean the blood.
<b>(an) Exchange</b>	The draining out of used liquid and the adding of fresh liquid in a peritoneal dialysis session.
<b>Fistula</b>	A fistula is made by a surgeon joining a person's vein and artery together under the skin in the arm or leg, to make the access point for haemodialysis.
<b>Haemodiafiltration (HD)</b>	A process to remove toxins and excess fluid from a person's body by pumping the blood from the body, to a haemodialysis machine, taking out the waste products, and pumping cleaned blood back into the body.
<b>Home haemodialysis (HHD)</b>	Haemodialysis carried out in the person's home.
<b>Centre haemodialysis (CHD)</b>	Haemodialysis carried out in the hospital.
<b>Nephrologist</b>	A doctor who looks after people with kidney problems.
<b>PD tube (PD)</b>	See Catheter.
<b>Peritoneal dialysis</b>	A process using natural processes inside the body to filter waste products from the blood as it moves around the internal organs and intestine into dialysis fluid (dialysate) drained in, and out, of the belly.
<b>Renal</b>	Refers to anything to do with the kidneys.
<b>Kidney replacement therapy (KRT)</b>	A treatment that does some of the job of the kidneys.
<b>Peritoneal (or Tenckhoff) catheter</b>	See Catheter.
<b>Stage 5 CKD</b>	Another term for established kidney failure.
<b>Transplantation</b>	A surgical operation to add a kidney donated from another person.
<b>Uraemia</b>	A condition where the body's waste products and excess water are not being removed from the blood.

## 12. Further information and patient resources

Below are other websites and information people find helpful about living with kidney disease.

### **Kidney information and support networks**

Kidney Failure Explained – 6th Edition, Wild J, Fluck R. (2019) Kidney Care UK.

Help! I've Got Kidney Failure – 3rd Edition. Fluck R, Wild, J. (2017) Kidney Care UK

Kidney Patient Support Charity [www.kidneycareuk.org/](http://www.kidneycareuk.org/)

Kidney Research UK [kidneyresearchuk.org/kidney-health-information/](http://kidneyresearchuk.org/kidney-health-information/)

National Kidney Federation Charity [www.kidney.org.uk/](http://www.kidney.org.uk/)

NHS Think Kidneys [www.thinkkidneys.nhs.uk/](http://www.thinkkidneys.nhs.uk/)

NHS Chronic Kidney Disease [www.nhs.uk/conditions/kidney-disease/](http://www.nhs.uk/conditions/kidney-disease/)

NHSinform Chronic Kidney Disease [www.nhsinform.scot/illnesses-and-conditions/kidneys-bladder-and-prostate/chronic-kidney-disease](http://www.nhsinform.scot/illnesses-and-conditions/kidneys-bladder-and-prostate/chronic-kidney-disease)

Kidney Patient Involvement Network [www.sharedialysis-care.org.uk/sharehd/sharehd-news/kidney-patient-involvement-network-kpin](http://www.sharedialysis-care.org.uk/sharehd/sharehd-news/kidney-patient-involvement-network-kpin)

Renal Association Patient Involvement [www.renal.org/about-the-renal-association/](http://www.renal.org/about-the-renal-association/)

Renal Registry Patient Information [www.renalreg.org/patient-info/](http://www.renalreg.org/patient-info/)

### **Social care and caring for others with kidney and health problems**

People caring for others [www.carersweek.org/about-us](http://www.carersweek.org/about-us)

Social Care Support [www.nhs.uk/conditions/social-care-and-support-guide/](http://www.nhs.uk/conditions/social-care-and-support-guide/)

Sue Ryder Palliative Care [www.sueryder.org/how-we-can-help](http://www.sueryder.org/how-we-can-help)

NHS Advance Care Statements

[www.nhs.uk/conditions/end-of-life-care/advance-statement/](http://www.nhs.uk/conditions/end-of-life-care/advance-statement/)

### **The Yorkshire Dialysis Decision Aid (YoDDA) and Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) project websites.**

About the YoDCA (2017-2020) and YoDDA (2010-2015) studies

[www.kidneyresearchyorkshire.org.uk/home/yodca/](http://www.kidneyresearchyorkshire.org.uk/home/yodca/)

[www.youtube.com/watch?reload=9&v=ppRWzD6yJLw](http://www.youtube.com/watch?reload=9&v=ppRWzD6yJLw)

# 13. Research and policy papers used for The Dialysis Decision Aid Booklet

The DDA used facts from the research below to design this booklet so that it helps people reason about which dialysis option fits best into their daily life.

## Kidney Disease Policy and Treatment

1. NICE Guideline – Renal replacement therapy and conservative management (NG107). (2019).
2. NICE Quality Standard 72 - Renal replacement services for adults (updated 2018).
3. UK Renal Registry. The 21st annual report - the renal association (2017); Bristol UK.
4. NHS Blood and Transplant. Annual report: living donor kidney transplantation 2018/2019. NHS England , UK (2020)
5. NHS Blood and Transplant. Annual report: kidney transplantation 2018/2019. NHS England, UK (2019)
6. Warwick G, Mooney A, Russon L, Hardy W. Clinical practice guidelines - planning, initiating and withdrawal of renal replacement therapy; UK Renal Association 6th Edition (2017)
7. Locatelli F, Carfagna F, Del Vecchio L, La Milia V. Haemodialysis or haemodiafiltration: that is the question. *Nephrol Dial Transplant*. 2018 Nov 1;33(11):1896-1904. doi: 10.1093/ndt/gfy035.
8. Nistor I, Palmer SC, Craig JC, et al. Haemodiafiltration, haemofiltration and haemodialysis for end-stage kidney disease. *Cochrane Database of Systematic Reviews* 2015, Issue 5. Art. No.: CD006258. DOI: 10.1002/14651858.CD006258.pub2.
9. Suwabe T, Barrera-Flores FJ, Rodriguez-Gutierrez R, et al Effect of online hemodiafiltration compared with hemodialysis on quality of life in patients with ESRD: A systematic review and meta-analysis of randomized trials. *PLoS ONE* (2018) 13(10): e0205037.
10. Wilkie M, Barnes T. Shared hemodialysis care. Increasing patient involvement in center-based dialysis. *CJASN* September 2019, 14 (9) 1402-1404.
11. Brown EA, Wilkie M. Assisted peritoneal dialysis as an alternative to in-center hemodialysis. *Clin J Am Soc Nephrol*. 2016 Sep 7; 11(9): 1522–1524.
12. Lambie M, Teece L, Johnson DW, et al. Risks of encapsulating peritoneal sclerosis accounting for the competing risk of death. *Nephrology Dialysis and Transplant*. 2019. 34: 1585-1591.
13. Hussain JA, Mooney A, Russon L (2013) Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. *Palliat Med*. 27(9): 829-39
14. Murtagh FEM, Burns A, Moranne O, et al. Comprehensive conservative care in end-stage kidney disease. *CJASN*. 2016: 1909-1914
15. NICE Guidance 142 - End of life care for adults (2019)
16. NICE Pathways - End of life care for people with life limiting conditions. (2019).
17. O'Halloran P, Noble H, Norwood K, et al. Advance care planning with patients who have end-stage kidney disease: a systematic realist review. *Journal of pain and symptom management*. 2018; 56:795-807.e18.
18. Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO controversies conference on supportive care in chronic kidney disease: developing a roadmap to improving quality of care. *Kidney Int*. 2015. 88:447-59.

19. Hole B, Hemmelgarn B, Brown et al. Supportive care for end-stage kidney disease: an integral part of kidney services across a range of income settings around the world. *Kidney International Supplements*. 2020; 10: e86-e94.

### **Experiences of making dialysis decisions and patient decision aids**

20. Winterbottom A, Gavaruzzi T, Mooney A... Bekker HL. Patient acceptability of the Yorkshire Dialysis Decision Aid (Yodda) Booklet: a prospective non-randomised comparison study across 6 predialysis services; *Peritoneal Dialysis International*, 2016; 36:4:374-381.
21. Winterbottom AE, Mooney A, Russon L... Bekker HL. Critical review of leaflets about conservative management used in UK renal services. *Journal of Renal Care*. 2020.
22. Winterbottom A, Bekker HL, Conner Mark, Mooney A, Evaluating the quality of patient information provided by Renal Units across the UK. *Nephrology, Dialysis and Transplantation*. 2007; 22: 2291-2296.
23. Gavaruzzi T, Summers B, Latchford G... Bekker HL. Is it better to present dialysis treatment choices in an option or attribute format? An experimental Study. International Shared Decision Making Conference, NL (19-22th June 2011)
24. Winterbottom A, Bekker HL, Conner M, Mooney A. Choosing dialysis modality: decision making in a chronic illness context. *Health Expectations*, 2014,17:5:710-23.
25. Durand M-A, Bekker HL, Casula A, et al. Can we routinely measure patient involvement in treatment decision making in chronic kidney care? A service evaluation in 27 renal units in the UK. *Clinical Kidney Journal*. 2016; 1-8.
26. Brown E, Bekker HL, Davison S, et al. Supportive care communication strategies to improve cultural competence in shared decision making. *Clin J Am Soc Nephrol*. 2016; 11:1902-1908.
27. Morton RL, Tong A, Howard K, et al. The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *British Medical Journal*, 2010, 340:c112,
28. Finderup J, Jensen JKD, Lomborg K. Developing and pilot testing a shared decision-making intervention for dialysis choice. *Journal of Renal Care* 2018; 44: 152-161
29. Fortnum D, Grennan K, Smolonogov T. End-stage kidney disease patient evaluation of the Australian 'My Kidneys, My Choice' decision aid. *Clin Kidney J*. 2015; 8: 469-475
30. Loisele M-C, Michaud C, O'Connor A. (2016). Decisional needs assessment to help patients with advanced chronic kidney disease make better dialysis choices. *Nephrology Nursing Journal*, 43(6), 463-477, 493.
31. Walker RC, Morton RL, Palmer SC, et al. A discrete choice study of patient preferences for dialysis modalities. *Clin J Am Soc Nephrol*. 2018; 13:100-108
32. Bekker HL. The loss of reason in patient decision aid research: do checklists affect the validity of informed choice interventions? *Patient Education and Couns* 2010; 78:357-364.
33. Bekker H, Thornton JG, Airey CM, et al. Informed decision making: an annotated bibliography and systematic review. (1999) UK: Health Technology Assessment Number 3. NHS R&D.
34. Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2017, Issue 4. Art. No.: CD001431.

# 14. Patient information available from Kidney Research UK

We are the largest charity dedicated to kidney research in the UK. Our vision is to free lives from kidney disease. We fund research into all aspects of kidney disease – from understanding the condition, to how we can prevent and treat it. We want to discover better, kinder treatments.

Our kidney health information resources are 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.

Listed below are other resources available on our kidney health information web page, for more information visit:

[www.kidneyresearchuk.org/kidney-health-information](http://www.kidneyresearchuk.org/kidney-health-information)

## **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.

## **Kidney Voices for Research**

Patients are at the heart of everything we do. You are experts in living with kidney disease and this insight is essential to inform and develop the best research. If you want to use your experience to help other patients, join our growing online community of patient research advisors. To find out more visit: [www.kidneyresearchuk.org/kidneyvoices](http://www.kidneyresearchuk.org/kidneyvoices)

## **Dialysis Decision Aid Booklet**

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

Website: [www.kidneyresearchuk.org/health-information](http://www.kidneyresearchuk.org/health-information)

Email: [kidneyhealth@kidneyresearchuk.org](mailto:kidneyhealth@kidneyresearchuk.org)

Telephone: 0300 303 1100

Hard copies of the Dialysis Decision Aid are available to post to UK addresses only.

A number of countries have translated the booklet into their own language.

Please contact us if you would like further information. Please contact Professor Bekker ([h.i.bekker@leeds.ac.uk](mailto:h.i.bekker@leeds.ac.uk)) if you wish to modify the DDA2020 or use it in research and quality improvement projects.

# Thank you from the YoDDA & YoDCA research teams

YoDDA and YoDCA research teams are grateful to all the patients and health professionals who took part in our research, and commented on drafts and updates of our decision aids. Their views and experiences helped make this booklet useful for people making this decision.

YoDDA and YoDCA research team members are:

- **Patient Representatives:** Dennis Crane\* (National Kidney Federation), Ken Tupling (Sheffield Kidney Patients Association), Richard Williams (Patient Representative Leeds NHS Trust Kidney Unit).
- **Health Professionals:** Andrew Mooney, Gary Latchford (Leeds NHS Trust); Martin Wilkie, Lorraine Edwards (Sheffield NHS Trust); Mark Lambie (University Hospital of North Staffordshire); Simon Davies (University of Keele); Nigel Mathers (University of Sheffield), Lynne Russon (Palliative Consultant, Wheatfields Hospice), Vicki Hipkiss (Renal Nurse Specialist, Bradford Teaching Hospitals Foundation Trust), Jeanette Finderup (Clinical Nurse Specialist, Aarhus University Hospital).
- **Decision Scientists:** Hilary Bekker, Anna Winterbottom, Teresa Gavaruzzi, Barbara Summers (University of Leeds); Anne Stiggelbout (University of Leiden).
- **Health Informatics and Design:** Susan Clamp (University of Leeds); Owen Johnson, Scott Jones (x-lab, Nikki Ruddock (Senior Designer, LTH Medical Illustration).
- **Health Services Research:** Paul Baxter, David Meads (University of Leeds), Louese Dunn (Sheffield NHS Trust), Lucy Ziegler (Associative Professor in Palliative Care, University of Leeds).

\* The YoDDA team would like to acknowledge the invaluable contributions from Dennis Crane MBE, one of the patient expert advisors to the project, who sadly died on 20 January 2017.

We would also like to thank Titman Firth Creative Marketing for the design and Quanta Dialysis Technologies for funding the printing of the Dialysis Decision Aid Booklet 2020.



Call 0300 303 1100  
[www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

Registered Office: Nene Hall, Lynch Wood Park, Peterborough PE2 6FZ.  
Kidney Research UK is a limited company registered in England.  
Registered company no. 905963. Registered charity no. 252892.  
Registered Scottish charity no. SC039245.

