

# A Dialysis and Conservative Care Decision Aid: Living with Kidney Disease



**The YoDCA Study Booklet**

# About the Booklet



This booklet is for people with chronic kidney disease that is getting worse, and who are making decisions between **conservative care** or **dialysis** pathways. It aims to help people and their families talk with health professionals about these different pathways and why one option suits a person's life better than the other.

The booklet has been developed by the Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) study team. There are more details about the study at the end of the booklet (see pages 26-27).

This research was funded by:



More copies of this booklet are available from Kidney Research Yorkshire's website [www.kidneyresearchyorkshire.org.uk/home/yodca](http://www.kidneyresearchyorkshire.org.uk/home/yodca) or ask your kidney team.

Please write your name in the space below. Then the booklet can be returned to you if you leave it in clinic.

**Name:** .....

**Kidney unit:** .....

## Disclaimer:

Every effort has been made to provide accurate information at the date of publication (July 2020). However, facts about managing kidney disease with dialysis and conservative care, and how you want to live your life, can change over time. Check with your kidney team about the facts you are using to make your decisions.

Date of next content review and update: January 2022.

# Contents



People use this booklet in different ways. Most people read it a few times, on their own and with family and friends. People use the prompts in this booklet to talk with health professionals and plan which option fits into their everyday life best <sup>[1,2]</sup>.

To help people focus on what is important to them about their experience of illness and treatment decisions, the booklet is split into sections:

- **Section A:** Chronic and Established Kidney Disease
- **Section B:** Conservative Care and Dialysis
- **Section C:** My Decisions about Conservative Care and Dialysis
- **Section D:** Next Steps for Care
- **Further Information:** Glossary, Patient Information, References, Study Details.

Each section has information and a decision map, and prompt to help people think through this decision:

**Information** and tables provide facts about treatment for kidney disease. Some sentences have numbers in brackets like this: <sup>[1,2]</sup>. These numbers link the information in the sentence to references. The references or sources for these facts are listed on page 24-25.

**Decision maps** show the focus of each section and how it links with other information in the Booklet.

**Prompts** help people note down any questions and thoughts that are important to them when making this decision.

# Section A: Chronic and Established Kidney Disease



This section has information about chronic and established kidney disease, and how kidney professionals can help people manage their kidney disease.

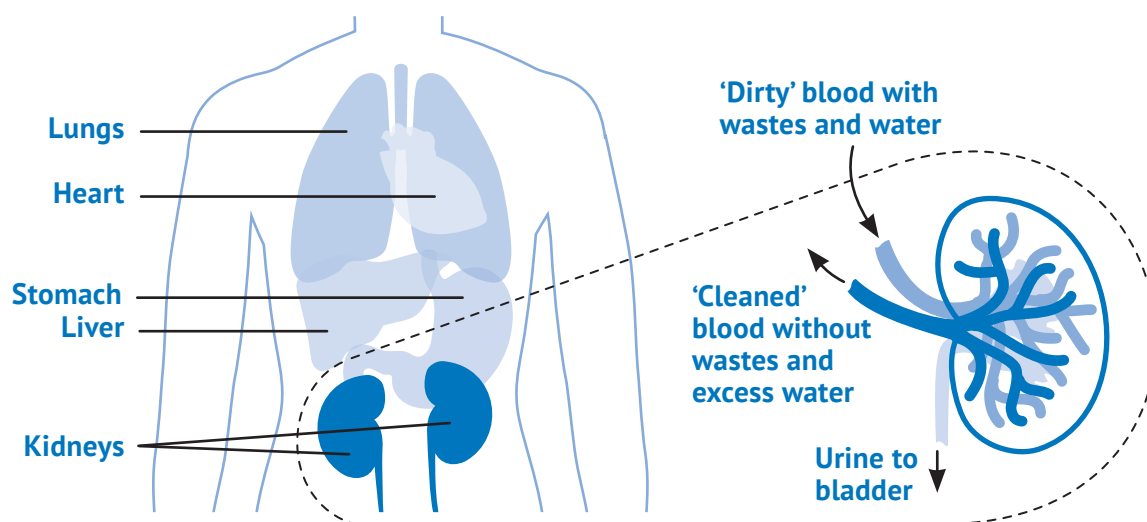
Chronic kidney disease (CKD) is a long-term health problem where people's kidneys slowly stop working (see Picture 1). Damaged kidneys cannot do their usual jobs to keep our bodies healthy. The types of jobs that kidneys do are:

- Filter and clean the blood so waste products (toxins) and excess water can leave our bodies as urine
- Control the balance of water and minerals (e.g. potassium, sodium) to keep our bodies well
- Make hormones that control other functions (e.g. blood pressure, anaemia)
- Balance acidity levels (pH) in the blood
- Control the calcium levels the body needs for healthy bones.

Health professionals who are expert in managing kidney problems care for people with CKD. They might be called a specialist kidney, renal or nephrology doctor, nurse, dietician, psychologist or therapist. CKD is a life-long illness, and kidney units work with other health professionals to manage people's health as they get older (old-age or geriatric professionals), if they have other health problems, their kidney function gets worse (palliative care professionals), or kidney treatments stop working (community-based health and social care professionals).

Established kidney disease (EKD) is the name used to describe CKD that is getting worse, when the kidneys gradually stop working. It is discussed in more detail later in this section.

**Picture 1: Where the kidneys are in the body and how the kidney works**



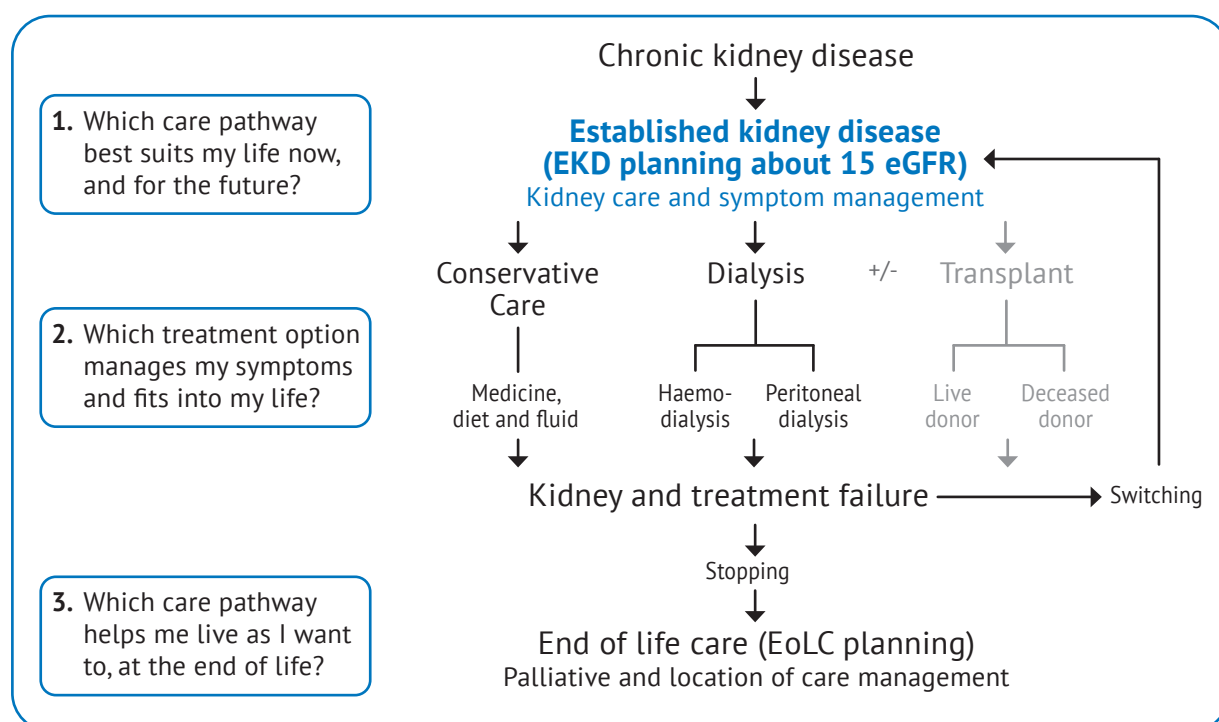
## Making Treatment Decisions with Kidney Professionals

Kidney professionals and people with CKD make decisions together about the treatments that will fit best into their everyday life to a) protect their kidneys, b) slow down damage to their body from losing kidney function, and c) manage any symptoms from their CKD getting worse.

These decisions help people plan their EKD management with their kidney professionals along a care pathway.

The decision maps in this booklet can help people see the different care pathways for people with CKD over time <sup>[1,2]</sup> (see Decision Map 1).

### Decision Map 1: Planning Care Pathway and Treatment Decisions for People with EKD



Kidney professionals use details from people’s kidney test results, experience of symptoms, other health problems or illnesses, and any lifestyle changes to give information about different options and care plans.

Some decisions happen often as part of CKD care, such as adjusting diet, medicines, fluid and exercise, to keep kidneys as healthy as possible (see Table 1). Other decisions happen less often, such as a change of care pathway when tests show CKD is getting worse, or treatments are not working as well as they did (see Section B).

**Table 1: Tips For Keeping Kidneys as Healthy as Possible** <sup>[3]</sup>

**To slow down the loss of kidney function:**

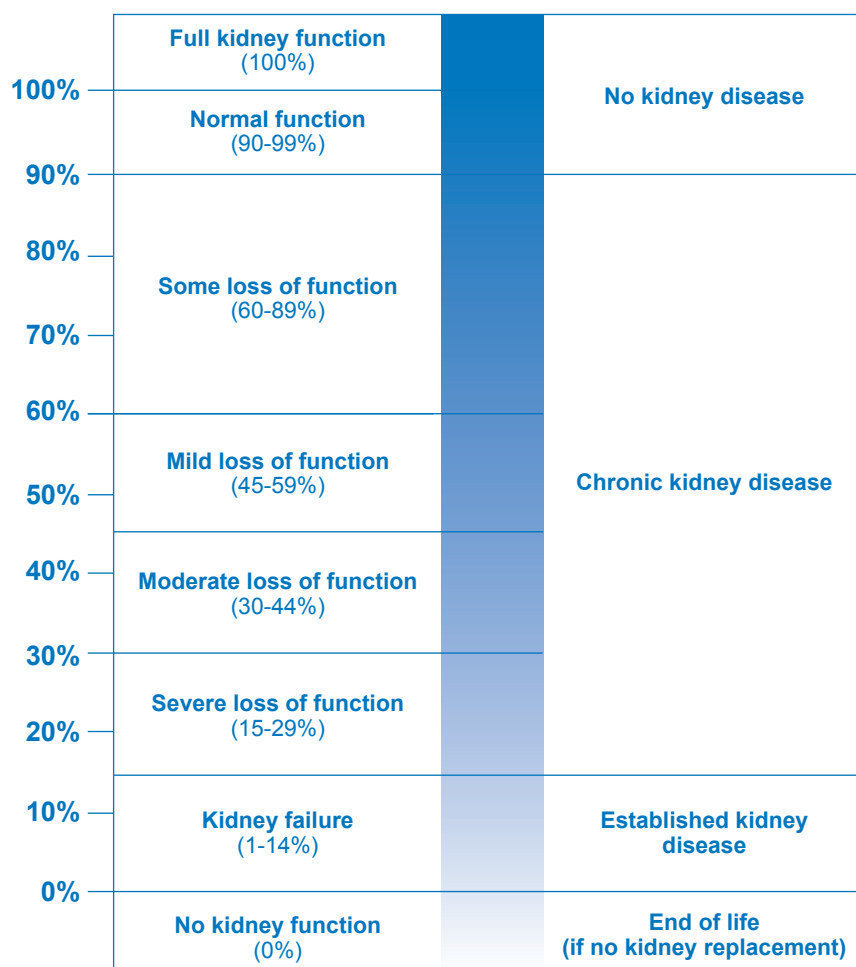
- Go to your regular kidney unit appointments - monitoring your well-being and regular tests can pick up changes to your health before you get symptoms
- Check your blood pressure at home or get it checked regularly, and take blood pressure medications - high blood pressure damages kidneys
- Ask pharmacists about any 'over the counter' medicines and 'natural' remedies you are planning to take, to check if they can damage the kidneys in people with EKD
- Follow the instructions for taking all medications your doctors give you
- Have a winter flu jab every autumn - people with EKD are more likely to get infections
- Get advice from a pharmacist, GP or kidney team about treating infections, high temperatures and diarrhoea quickly - getting dehydrated can damage the kidneys
- If you have diabetes, avoid high blood sugar levels - diabetes damages the blood vessels in kidneys
- Give up smoking or at least cut down - smoking speeds up kidney damage
- Give up alcohol or at least cut down - alcohol speeds up kidney damage
- Do some exercise 2-3 times a week - regular exercise helps keep kidneys healthy
- Keep a healthy weight - being overweight means your body, and kidneys, have to work harder
- Cut down on salt - salt can lead to high blood pressure which damages the kidneys.

## Established Kidney Disease

If a person's CKD worsens, it means their kidney function keeps getting lower, and this change is known as **kidney failure**. Kidney function is worked out from regular tests on estimated glomerular filtration rate (eGFR) and albumin to creatinine ratio (ACR). When a person's eGFR gets to about 15, the CKD has worsened to a stage sometimes called advanced or established kidney disease (EKD) [1,2]. Some people think about kidney function as a percentage, going from 100% (fully functioning) to 0% (no function; see Picture 2) [1,2].

When people are told they have EKD, it can affect their lives, how they feel, and the lives of those around them. People can feel shock, grief and denial at first. Some people find it difficult to concentrate and think clearly. It is common for people to experience anxiety, depression, concerns about body image, loss of self-confidence, and a loss of interest in sex. These feelings and problems may go away by themselves as people get used to living with EKD. Some people find sharing their experiences with their kidney team, patient support groups and their family can be useful (see page 23 for support groups).

**Picture 2: Loss of Kidney Function and Changes to Kidney Disease Stage [2]**



## Kidney Care and Symptom Management

People with EKD have regular meetings with kidney professionals to monitor how the loss of kidney function is affecting their body and health, and any side effects of treatments. Some people with EKD may not feel ill or know their symptoms can be linked to EKD (see Table 2). The regular check-ups include blood, urine and blood pressure tests, monitoring of symptoms, and changes to everyday life.

Many professionals help people manage their loss of kidney function and the symptoms caused by EKD. These include specialist teams of kidney (sometimes known as renal or nephrology) doctors and nurses, dieticians, occupational therapists, clinical psychologists, counsellors, social workers, GP, community nurses, pharmacists and physiotherapists. Different kidney units organise their EKD care and services in different ways. All kidney units follow national guidance about the care they offer [e.g. NICE NG107 4].

**Table 2: Managing Symptoms of Kidney Disease** <sup>[5,6]</sup>

Symptoms	Treatments and Therapies
Tiredness, low energy, fatigue, feeling cold	Tablets, injections for iron balance
Itching	Tablets, creams, psychological support
Nausea, vomiting, loss of weight or appetite	Tablets, support with managing protein and nutrients in diet
Swollen legs	Tablets, control of fluid, diet and salt
Memory or concentration loss, sleep problems	Tablets, monitoring, psychological support
Muscle and joint pain	Tablets, psychological support
Leg cramps, restless legs	Tablets, support with diet, psychological support
Back pain	Monitoring, support with fitness, psychological support
Dizziness, visual problems, headaches	Tablets, monitoring, psychological support, expert support for eyes
Shortness of breath	Tablets
Loss of muscle strength	Monitoring, support with fitness
Muscle spasms, stiffness	Tablets, support with fitness and diet
Loss of sex drive	Monitoring, psychological support
Need to urinate more often	Tablets, support with diet and fluid



## Section B: Conservative Care and Dialysis

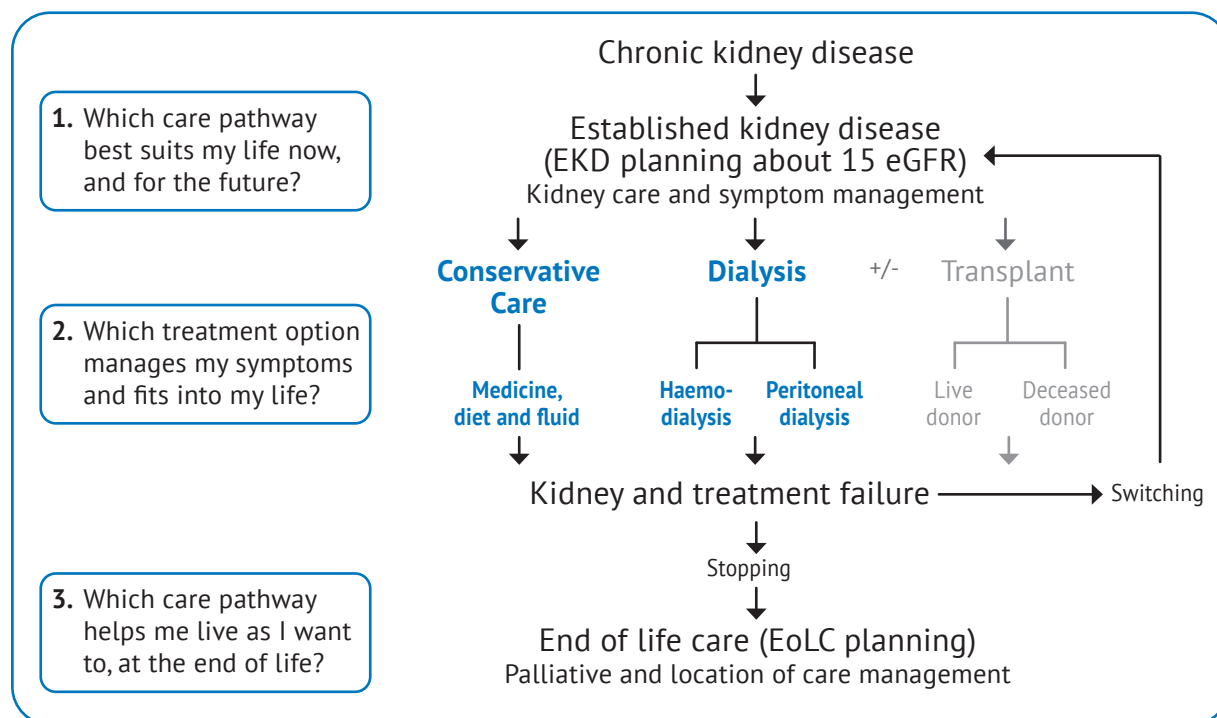


When people are told their CKD is getting worse, they can find it difficult to understand what this means for their health and managing their EKD in the long term. Making decisions about care can be difficult because of a) the speed at which EKD gets worse, b) the chance that treatment can slow down the loss of kidney function, c) the way treatment side effects vary from person to person, d) managing other health conditions like diabetes or problems with the heart and arteries, and e) the fact that not all people with kidney disease have symptoms.

Kidney professionals help people cope with their illness, and talk with them about which care pathway suits them best, based on their kidney test results, general well-being, daily activities and future plans.

This section has information for people deciding between the **conservative care** and **dialysis** pathways to manage their EKD (see Decision Map 2).

### Decision Map 2: Deciding Between Conservative Care and Dialysis Pathways



Kidney professionals carry out tests to see if people are suitable for a kidney transplant. A transplant can extend a person's life more than dialysis and conservative care (see Box 1). Talk with your kidney team about whether a kidney transplant is an option for you. This booklet is for people who have chosen to actively manage their kidney disease and are **not** suitable for a transplant.

## Box 1: Kidney Transplant Option

**Kidney transplant** is when a kidney is taken from a person without kidney disease (the donor) and put into the body of a person with kidney disease (the recipient). Kidney transplant operations are done by surgeons. The transplanted kidney is placed near to the kidneys in the recipient's body. Not everyone with kidney disease can have a kidney transplant. As people get older, or have 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) rejecting the transplanted kidney. Transplanted kidneys do the jobs needed to keep the body healthy. They do enough work so people do not have to restrict their diet and fluid in the same ways as they did 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 transplant list wait for 2-3 years <sup>[7]</sup>. 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 when they have a transplant <sup>[7]</sup>.

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 one year, about 94% of people (94 out of 100) with a DCD kidney have a functioning kidney, and about 98% of people (98 out of 100) with an LKD have a functioning kidney <sup>[7]</sup>. 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 <sup>[8, 9, 10]</sup>. People whose transplanted kidney starts to fail then make decisions about kidney transplant, dialysis and conservative care.

## Planning How to Manage EKD

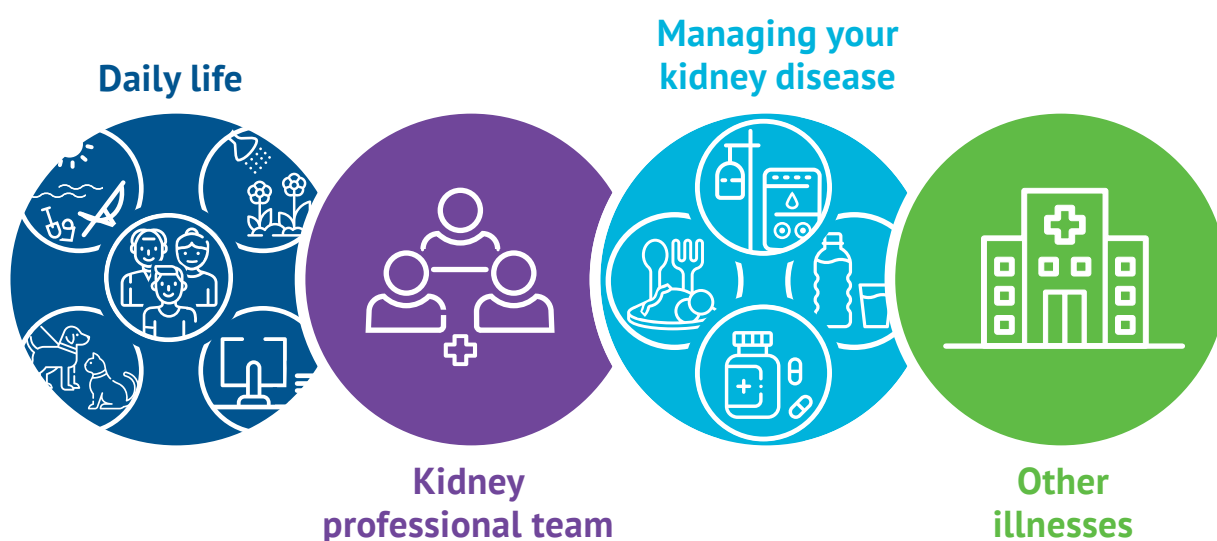
Kidney teams set aside times to meet with people, and their families when deciding to have or not have **conservative care** or **dialysis**. They want to help people decide about how best to manage their EKD and symptoms. It is important people choose a treatment to fit with their values and the way they want to live their life (see Picture 3). These treatments do not cure EKD.

Both pathways:

- aim to keep people well for as long as possible, in a way that fits people's values and daily needs
- include regular check-ups with kidney professionals, tests of kidney function, monitoring of symptoms, and updates on the effect of treatments and their side effects on people's daily life
- need adjusting over time as people get older, have other illnesses, make different life choices, and some treatments stop working
- help people to manage symptoms from their EKD (see Table 2).

The two pathways manage EKD in different ways, and have different effects on people's experience of illness, treatment choices, daily life and length of life (see Table 3).

**Picture 3: Thinking about what is important to you in your life**



**Table 3: Summary of management of EKD with conservative care and dialysis pathways**

	<b>Conservative Care Pathway</b>	<b>Dialysis Pathway</b>
<b>Treatments</b>	Uses medicines, diet and fluid management, and other treatments to keep the kidneys as healthy as possible (see Table 1) and manage EKD symptoms (see Table 2).	Uses equipment to clean people's blood. Dialysis does about 10% of the work of a healthy kidney (see Table 1). Dialysis and other treatments help manage EKD symptoms (see Table 2).  People have an operation to make an access point so dialysis equipment can be used: a <b>fistula</b> in an arm or leg for haemodialysis (HD), or a <b>catheter</b> in the belly for peritoneal dialysis (PD).
<b>Kidney care routines</b>	People who choose conservative care go to their kidney unit for regular check-ups. People may spend some time each day managing their EKD symptoms (see Table 2).	People who choose dialysis go to their kidney unit for regular check-ups. People spend a few hours each day managing their EKD symptoms, and extra time having dialysis on some days or every day. Some people travel to their kidney unit to have dialysis.
<b>Daily routines</b>	People add extra treatments when they are needed to manage the symptoms of kidney failure and loss of kidney function.	People add a dialysis treatment routine into their usual EKD care and daily life. People add extra treatments when they are needed to manage the symptoms of kidney failure and loss of kidney function.
<b>Life expectancy</b>	Conservative care does not lengthen life. People's length of life depends on how fast their kidneys stop working, their age, ability to do daily tasks, and other illnesses <sup>[11]</sup> .	Dialysis lengthens life in people who are generally fit and well. It might not lengthen life for people who are older, have other illnesses and have difficulty looking after themselves <sup>[11,14]</sup> .
<b>Impact on daily life</b>	The way people feel about their everyday life seems to stay the same or may get slightly better on this pathway <sup>[12,13]</sup> .	The way people feel about their everyday life seems to stay the same or may get slightly worse on this pathway <sup>[12,15]</sup> .

## Adjusting and Switching Treatments

After people decide which treatment pathway to have, kidney professionals work with them to find the best way to fit treatments and kidney care into their lives. Kidney teams support people whether they are having their care at home (e.g. with assisted care) or at a kidney unit (e.g. with transport). Over time, people with EKD make many decisions with their kidney team about adjusting routines and switching treatments. People who decide to have dialysis choose which type fits best with their lifestyle. See the Dialysis Decision Aid for facts about haemodialysis (HD) and peritoneal dialysis (PD) options <sup>[2]</sup>. Some people think about what will happen if they switch pathways from conservative care to dialysis, or dialysis to conservative care, or stop treatments.

As people’s EKD gets worse, they may have other health problems, their lifestyle may change, treatment side effects may impact on their daily activities, or the treatment they have may no longer work well enough to cope with the body’s loss of kidney function. People having dialysis may talk with kidney professionals about switching to another type of dialysis or stopping dialysis treatment. Kidney professionals and people with kidney failure make plans about **end of life care**, often with help from other health professionals and services.

**Table 4: Your reasons for choosing either of the care pathways**

Use this table to jot down your views about the pathways. Rate how important each reason is to you (\*somewhat important, \*\*important, \*\*\*very important)

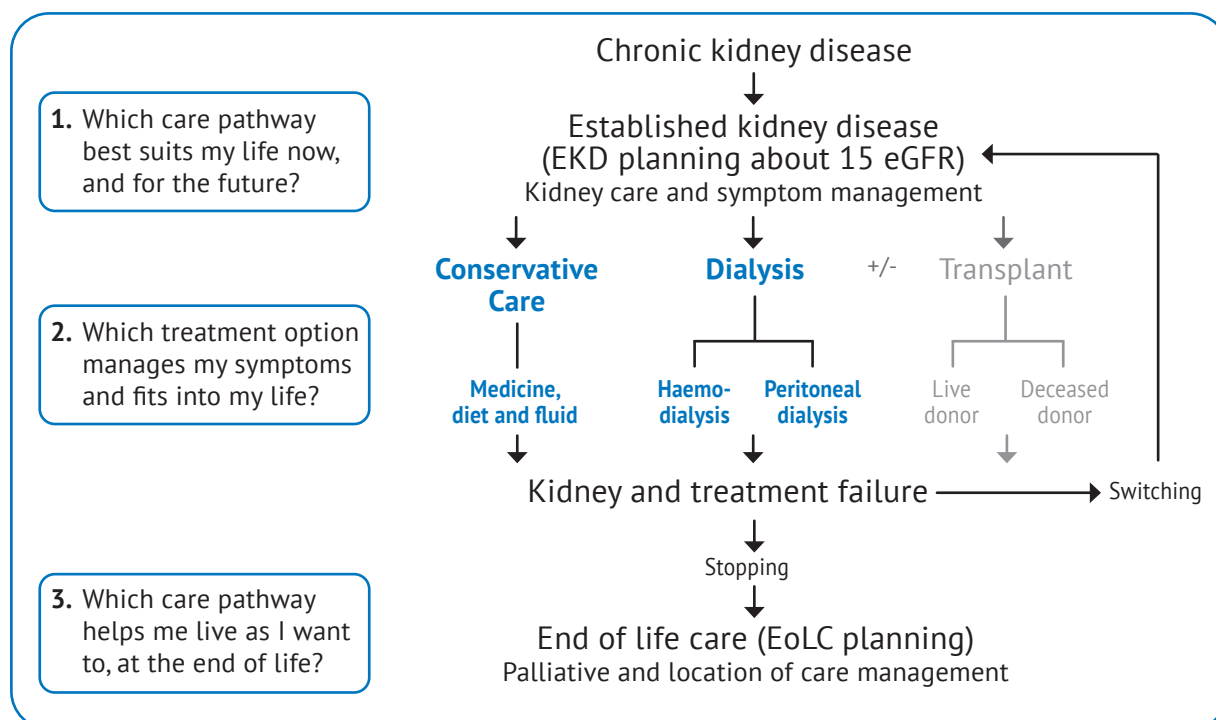
<b>Reasons for choosing Conservative Care Pathway</b>	<b>Importance (*/**/*** )</b>
<b>Reasons against choosing Conservative Care Pathway</b>	<b>Importance (*/**/*** )</b>
<b>Reasons for choosing Dialysis Pathway</b>	<b>Importance (*/**/*** )</b>
<b>Reasons against choosing Dialysis Pathway</b>	<b>Importance (*/**/*** )</b>

# Section C: My Decisions about Conservative Care and Dialysis



The information in this section will help you think about which pathway suits you best, and how you want to work with kidney professionals to plan your EKD management now, and for the future.

## Decision Map 2: Deciding Between Conservative Care and Dialysis Pathways



## Making Conservative Care and Dialysis Pathway Decisions

Kidney teams help people plan and decide on their treatment before it needs to start. Planning means people are more likely to choose the treatment that best suits their lifestyle. It gives people time to talk about what is important to them about their lifestyle, health and different treatments. It gives kidney teams time to plan for any changes in the care of people's kidney disease. When people choose dialysis, planning gives the surgeons a chance to carry out an operation to prepare people's dialysis access points.

People's health is better if a treatment is planned and started before their kidney function gets worse. This can be a difficult decision for some people to make. It means weighing up what is important in their life with their experiences of kidney disease, symptoms and treatments. They have to think about how their EKD, health, well-being and lifestyle may change over time. Table 5 summarises the facts people compare when making a decision about the conservative care or dialysis pathway.

**Table 5: Summary of Conservative Care and Dialysis Care Pathways**

	<b>Conservative Care</b>	<b>Dialysis</b>
<b>EKD pathway</b>	Regular check-ups and monitoring; medicines; diet and fluid guidance; lifestyle support (EKD care).	Regular check-ups and monitoring; medicines; diet and fluid guidance; lifestyle support (EKD care).  Access point operation; equipment to clean blood; daily dialysis routines.
<b>EKD impact</b>	Manage symptoms, keep kidneys healthy.  Length of life follows natural course of person’s kidney failure.	Manage symptoms, keep kidneys healthy.  Lengthens life in those who are generally fit and well.
<b>Daily life impact</b>	Fit EKD care routines into daily life.  Feel the same or possibly slightly better about life.	Fit EKD care routines into daily life and have dialysis regularly.  Manage dialysis side effects; feel same or possibly worse about life.
<b>Other decisions</b>	Add treatments as kidneys fail and symptoms get worse.  Make advance care plans to manage care at end of life.	Peritoneal dialysis (PD) or haemodialysis (HD) decision.  Add treatments as kidneys fail and symptoms get worse.  Make advance care plans to manage care at end of life.
<b>Adjust or switch</b>	Adjust or switch treatments as symptoms get worse.	Adjust or switch treatments as symptoms get worse. Over time, may switch or stop HD and PD options.
<b>Value trade-offs</b> (see next page for more details)	On balance, is it worth fitting <i>EKD</i> routines into my life now, and in the future?	On balance, is it worth fitting <i>EKD</i> and <i>dialysis</i> routines into my life now, and in the future?

Medical studies measure a) the life expectancy of people with EKD, compared with groups of healthy people, b) the impact of kidney treatments on how quickly kidneys stop working, symptom control and side effects, and c) different ways people cope with EKD [16,17,18,19].

Different studies collect different facts in different ways. People who take part in these studies are usually chosen because of characteristics like age, sex, ethnicity, other health problems and/or treatment. These studies mean figures cannot be calculated for how well different pathways work for people with different characteristics. Ask your kidney professional if there are figures from studies of treatments that might be useful in your EKD treatment decisions. Use Box 2 on the next page to write down any notes or questions.

### My Trade-offs Between Conservative Care and Dialysis Pathways

Managing EKD and its symptoms means people fit daily treatments, visits to kidney units, and changes to diet and fluid routines into their lives. People decide on a pathway by balancing judgements about their kidney function and well-being with their feelings about what is most important in their lives now and for the future [20]. An example of a trade-off might be thinking about what is more important to you in your daily life now, as your kidney disease gets worse:

- The conservative care pathway means a chance to do daily activities (e.g. hobbies, family and pets, leisure and holidays) with fewer regular medical routines, until there is no kidney function left
- The dialysis pathway means fitting an extra set of medical procedures and routines around daily activities (e.g. hobbies, families and pets, leisure and holidays), with a chance of lengthening life when there is no kidney function left.

Given what you know about your EKD, and your reasons for and against each pathway (page 13), circle the answer for each option that best matches how you want to manage your EKD:

**Table 6: Thinking about which pathway will suit me best**

<b>Conservative care pathway</b>	Yes	No	Unsure
<b>Dialysis pathway</b>	Yes	No	Unsure



**Box 2: Prompts to help you talk with kidney professionals**

This page is to help you talk with kidney professionals about your kidney health, experiences of treatment, other health concerns and daily life. Talking to family and friends about the following topics can help you to work out if one option suits you better than another. Use the space below to write notes or questions to help you talk to your kidney professional.

My kidney function and kidney health:

My treatments and side effects:

My well-being and self-care:

My health and other illnesses:

My hobbies and lifestyle:

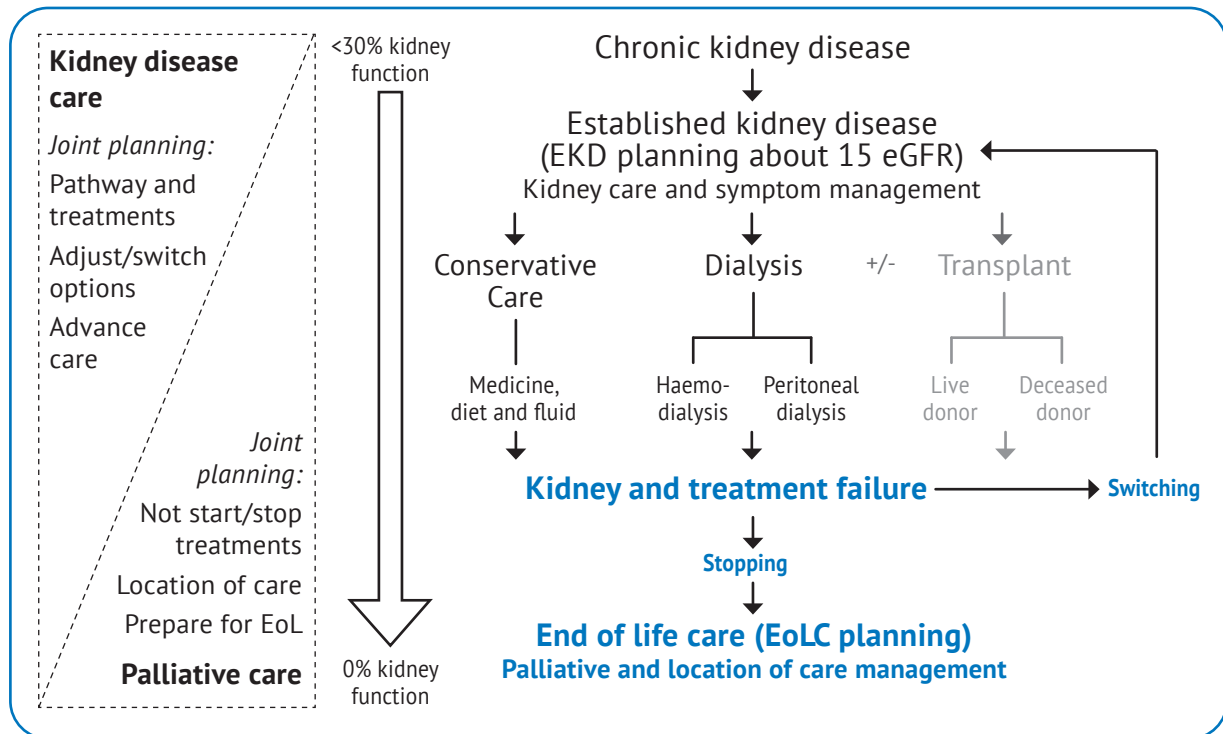
Other:

## Section D: Next Steps for Care



This section gives information about planning for changes in care and treatment after you have decided between conservative care and dialysis, and as your EKD gets worse over time.

### Decision Map 3: Changes in care and treatment as EKD gets worse



### Planning for Changes in Health with EKD

Over time, people with EKD can feel more unwell and less able to do their daily activities. People may need more treatments to manage more symptoms or may no longer be able to enjoy their hobbies and social activities. When these changes happen, people can have extra care to give them comfort and symptom relief. This type of care is called **palliative care**. It helps people keep a good quality of life and make care plans with health professionals and family at the right time before their kidneys fail. Palliative care options include:

- Controlling symptoms and pain relief
- Help carrying out daily tasks such as washing, eating and dressing
- Emotional, spiritual and psychological support
- Support for family and friends.

People on both the conservative care and dialysis pathways are asked to make **advance care plans** when they still feel well. These plans help kidney professionals and families know what treatments to change, start or stop. They can help give people the best possible quality of life for as long as possible. The plans are personal, written documents that are used to plan care with others. This way, everyone knows the person's wishes, even if they become unable to talk about their care.

Advance care plans can be made at any time, and people can change their minds about their decisions if their views change. Planning when you are well helps kidney teams, primary care (your GP), and community and palliative care services to organise the best care for you. Your GP, community nurse or kidney professionals will help you make an advance care plan that includes all the issues that may be important to you, such as:

- faith or spiritual beliefs that may influence care and death
- naming a person to make financial, personal and care decisions for you (lasting power of attorney), such as a will, funeral and arrangements for pets and family
- stating where you would prefer to die, i.e. home, hospital or hospice
- decisions about treatment you do or do not want at the end of life
- decisions about organs, tissue and/or body for donation.

### **Box 3: End of life care for people with worsening EKD**

Life expectancy for people with EKD is less than for healthy people. The most common cause of death for people with EKD is from another illness they may have such as cardiovascular disease, cancer or stroke <sup>[21]</sup>. Most people having dialysis have a longer life expectancy than people having conservative care.

When people have little or no kidney function left, and are not on dialysis, toxins and excess water build up in their body and they move towards the end of life. For people with no kidney function who stop dialysis, this withdrawal from life happens over about 10 days. For people with some kidney function left, this may happen over a few weeks or months.

Nurses and doctors help manage symptoms people experience, such as aches and pains. This stage of EKD management is known as **end of life care**. During the last few days at the end of life, people slip into a coma (fall unconscious), and when the toxins have built up in the blood, their heart stops beating, they gradually begin to withdraw from life and death happens.

# Preparing to Make Plans with Kidney Professionals about Your EKD Care

Use this page to note down what you want to share with kidney professionals about your daily life and values when planning treatment.

## Table 7: Your thoughts about making your pathway decision

Use the questions below to think about what else you need to know to make your decision about conservative care or dialysis now and in the future<sup>[22]</sup>.

Circle 'yes' or 'no' for each of these statements:

<ul style="list-style-type: none"><li>• Do you feel sure about the best choice for you? <b>Yes</b>                      <b>No</b></li><li>• Do you know the advantages and disadvantages of each option? <b>Yes</b>                      <b>No</b></li><li>• Are you clear about the advantages and disadvantages that matter most to you? <b>Yes</b>                      <b>No</b></li><li>• Do you have enough support and advice to make a choice? <b>Yes</b>                      <b>No</b></li></ul>
--

## Notes to help plan your care with kidney professionals and family:

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....



## Glossary

Below is a list of words health professionals use when talking about kidney disease and its treatment, together with their meaning and abbreviations that might be used.

Term	Description of Term	Abbreviation (where used)
<b>Advance care plan</b>	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 they become too unwell to decide or tell someone what they want.	ACP
<b>Automated peritoneal dialysis</b>	Dialysis that is usually carried out at night-time for about nine hours, automatically by a machine.	APD
<b>Chronic kidney disease</b>	A long-term condition where the kidneys do not work properly.	CKD
<b>Cognitive behaviour therapy</b>	A talking therapy that can help people manage their symptoms by changing thoughts and behaviours.	CBT
<b>Conservative care</b>	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>	Dialysis that is usually carried out about four times each day using bags of dialysis fluid (dialysate).	CAPD
<b>Dialysis</b>	A treatment that can remove toxins and excess water from the body.	
<b>End of life care</b>	End of life care involves treatment, care and support for people who are near the end of their life.	EoLC
<b>Established kidney disease</b>	Term used to describe chronic kidney disease getting worse and the kidneys gradually stop working (CKD stages 4/5).	EKD

<b>Estimated glomerular filtration rate</b>	This measures how well kidneys filter fluid and clean the blood.	eGFR
<b>Geriatric care</b>	Healthcare for older adults.	
<b>Haemodialysis</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, filtering out the waste products, and pumping the cleaned blood back into the body.	HD
<b>Home haemodialysis</b>	Haemodialysis carried out in the home.	HHD
<b>Centre haemodialysis</b>	Haemodialysis carried out in the hospital.	CHD
<b>Kidney Failure</b>	see 'Established Kidney Disease'.	
<b>Kidney replacement therapy</b>	A treatment that does some of the job of the kidneys.	KRT
<b>Nephrologist</b>	A doctor who looks after people with kidney problems.	
<b>Palliative care</b>	Care to manage symptoms, improve quality of life, support families and give comfort to people as their established kidney disease gets worse.	
<b>Peritoneal dialysis</b>	A process 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 peritoneal cavity. The peritoneum acts as a filter when a dialysis fluid (dialysate) is added to the peritoneal cavity.	PD
<b>Power of attorney</b>	A legal document that allows someone else to represent a person in financial, personal and care decisions.	PoA
<b>Renal</b>	Refers to anything to do with the kidneys.	
<b>Supportive care</b>	Care to improve the quality of life for people with chronic and established kidney disease, including those on dialysis and conservative care, and at end of life.	SC
<b>Transplantation</b>	A surgical operation to give someone a kidney donated from another person.	Tx

## Patient Information

### Local kidney team information

Nursing team: .....

Kidney doctors: .....

Local kidney unit: .....

Community kidney nurses: .....

### Other useful telephone numbers

Hospital switchboard: .....

Renal pharmacist: .....

Palliative care: .....

GP: .....

### Useful information for people with EKD, and their friends and family

Dialysis Decision Aid (YoDDA): [kidneyresearchuk.org/DialysisDecisionAid](http://kidneyresearchuk.org/DialysisDecisionAid)

Kidney Care UK: [kidneycareuk.org](http://kidneycareuk.org)

Kidney Patient Involvement Network: [kpin.org.uk](http://kpin.org.uk)

Kidney Research UK: [kidneyreserchuk.org](http://kidneyreserchuk.org)

Kidney Research Yorkshire: [kidneyresearchyorkshire.org.uk](http://kidneyresearchyorkshire.org.uk)

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

NHS Advance Care Statements: [nhs.uk/conditions/end-of-life-care](http://nhs.uk/conditions/end-of-life-care)

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

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

NICE Guidance: [nice.org.uk/guidance/ng107](http://nice.org.uk/guidance/ng107)

Renal Association: [renal.org/information-resources](http://renal.org/information-resources)

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

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

## References

### Research used to inform this booklet's content:

- [1] 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. *Peritoneal Dialysis International* 2016; 36:374-381
- [2] Kidney Research UK. The Dialysis Decision Aid Booklet: Making The Right Choices for You 2017; kidneyresearchuk.org/DialysisDecisionAid By 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
- [3] NICE Clinical Knowledge Summary: Chronic Kidney Disease. Published: 2009. Revised: May 2020. Available at: [cks.nice.org.uk/chronic-kidney-disease#!scenarioRecommendation:3](https://cks.nice.org.uk/chronic-kidney-disease#!scenarioRecommendation:3) (Accessed 30/06/2020)
- [4] NICE Clinical Guideline (NG107). Renal replacement therapy and conservative management. Published: October 2018. Available at: [nice.org.uk/guidance/ng107](https://www.nice.org.uk/guidance/ng107) (Accessed 09/06/2020)
- [5] Finderup J, Jensen JKD, Lomborg K. Developing and pilot testing a shared decision-making intervention for dialysis choice. *Journal of Renal Care* 2018; 44(3):152-161
- [6] Brown SA, Tyrer F, Clarke AL, Lloyd-Davies LH, Niyi-Odumosu FA, Nah RGQ, Stein AG, Tarrant C, Smith AC. Kidney Symptom questionnaire: development, content validation and relationship with quality of life. *Journal of Renal Care* 2018; 44(3):162-173
- [7] NHS Blood and Transplant. Annual Report on Kidney Transplantation for 2018/19. Published November 2019
- [8] Yasumura T, Oka T, Nakane Y, et al. Long-term prognosis of renal transplant surviving for over 10 yr, and clinical, renal and rehabilitation features of 20-yr successes. *Clin Transplant*. 1997;11(5 Pt 1):387-394.
- [9] Cacho DT, Piqué AA, Cusi LI, Reyes LI, Salinas FO, del Pozo RG. Living donor renal transplantation: prognostic factors on graft survival. *Transplant Proc*. 2005;37(9):3679-3681. doi:10.1016/j.transproceed.2005.10.071  
Cecka JM. The UNOS renal transplant registry. *Clin Transpl*. 2001;1-18.
- [10] NHS Blood & Transplant. Organ Donation and Transplantation Activity Report. Published 2018-9. NHS Blood & Transplant.
- [11] Hussain JA, Mooney A, Russon L. 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. *Palliative Medicine* 2013; 27(9):829-839



- [12] Iyasere O, Brown EA, Johansson L, Davenport A, Farrington K, Maxwell AP, Collinson H, Fan S, Habib A-M, Stoves J, Woodrow G. Quality of life with conservative care compared with assisted peritoneal dialysis and haemodialysis. *Clinical Kidney Journal* 2019; 12(2):262-268
- [13] Brown MA, Collett GK, Josland EA, Foote C, Li Q, Brennan FP. CKD in elderly patients managed without dialysis: Survival, symptoms, and quality of life. *Clinical Journal of the American Society of Nephrology* 2015; 10:260-268
- [14] Murtagh FM, Burns A, Moranne Om Morton RL, Naicker S. Supportive Care: Comprehensive Conservative Care in End-Stage Kidney Disease. *Clinical Journal of the American Society of Nephrology* 2016; 11(10):1909-1914
- [15] Da Silva-Gane M, Wellsted D, Greenshields H, Norton S, Chandna SM, Farrington K. Quality of life and survival in patients with advanced kidney failure managed conservatively or by dialysis. *Clinical Journal of the American Society of Nephrology* 2012; 7:2002-2009
- [16] Turin TC, Tonelli M, Manns BJ, Ravani P, Ahmed SB, Hemmelgarn BR. Chronic kidney disease and life expectancy. *Nephrology, Dialysis and Transplantation* 2012; 27:3182-3186
- [17] Cabrera VJ, Hansson J, Kliger AS, Finkelstein FO. Symptom Management of the Patient with CKD: The Role of Dialysis. *Clinical Journal of the American Society of Nephrology* 2017; 12:687-693
- [18] Subramanian L, Quinn M, Zhao J, Lachance L, Zee J, Tentori F. Coping with kidney disease - qualitative findings from the Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) study. *BMC Nephrology* 2017; 18(1):119
- [19] Tong A, Sainsbury P, Chadban S, Walker RG, Harris DC, Carter SM, Hall B, Hawley C, Craig JC. Patients' experiences and perspectives of living with CKD. *American Journal of Kidney Disease* 2009; 53(4):689-700
- [20] O'Connor AM, Stacey, D, Jacobsen MJ. Ottawa Decision Support Tutorial (ODST): Improving Practitioners' Decision Support Skills Ottawa Hospital Research Institute: Patient Decision Aids 2011 Accessed 12/05/2020: [decisionaid.ohri.ca/odsf.html](http://decisionaid.ohri.ca/odsf.html)
- [21] Kerr M, Matthews B, Medcalf JF, O'Donoghue D. End-of-life care for people with chronic kidney disease: cause of death, place of death and hospital costs. *Nephrology Dialysis & Transplantation* 2017; 32(9):1504-1509
- [22] Ferron Parayre A, Labrecque M, Rousseau M, et al. Validation of SURE, a four-item clinical checklist for detecting decisional conflict in patients. *Medical Decision Making* 2014; 34:54-62

## Study Details

### YoDCA study team and outputs

The Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) study team thank the people with EKD, and health professionals who took part in our studies to develop this booklet and commented on drafts. This project builds on our research since 2004 into people's experiences of making CKD treatment decisions and delivering kidney care ([yodda.leeds.ac.uk/Survey/Introduction](http://yodda.leeds.ac.uk/Survey/Introduction)).

### Expertise and organisations of the YoDCA study team

The YoDCA study team are:

**Dr Anna Winterbottom** (Research Psychologist, Leeds Teaching Hospitals NHS Trust)

**Professor Hilary Bekker** (Chair in Medical Decision Making, University of Leeds)

**Dr Andrew Mooney** (Consultant Renal Physician, Leeds Teaching Hospitals NHS Trust)

**Dr Lynne Russon** (Palliative Care Consultant, Wheatfields Hospice)

**Vicki Hipkiss** (Renal Nurse Specialist, Bradford Teaching Hospitals Foundation Trust)

**Richard Williams** (Patient Representative)

**Dr Lucy Ziegler** (Associate Professor in Palliative Care, University of Leeds)

**Dr Jeanette Finderup** (Clinical Nurse Specialist, Aarhus University Hospital)



### Conflicts of interest

The authors have no conflicts of interest, financial or otherwise. The patient decision aid was developed from research grant funded by KRY after external peer review. AM is a scientific advisor to Kidney Research Yorkshire (KRY) and was excluded from decisions about this application. The funders, authors and their employers do not stand to benefit from decisions people make after reading this booklet.

## Project funding

Our project **Designing a decision aid intervention to enable renal professionals to support patients making choices about conservative care** was funded by Kidney Research Yorkshire (ref 16-118; 2017-2020).

## Contact

Anna Winterbottom ([anna@winterbottom.co.uk](mailto:anna@winterbottom.co.uk)), Leeds Institute of Health Sciences - School of Medicine, University of Leeds, UK.

If you wish to undertake a research or quality improvement project using the decision aid booklet, contact Dr Winterbottom about collaboration.



## Study Team Twitter handles

Anna Winterbottom [@DrAWinterbottom](https://twitter.com/DrAWinterbottom)

Lucy Ziegler [@LucyZiegler3](https://twitter.com/LucyZiegler3)

Hilary Bekker [@BekkerHilary](https://twitter.com/BekkerHilary)

Jeanette Finderup [@finddrup](https://twitter.com/finddrup)

Research Centre for Patient Involvement [@ResCenPI](https://twitter.com/ResCenPI)

## Referencing the Dialysis and Conservative Care Patient Decision Aid

The Yorkshire Dialysis Decision and Conservative Care Aid Booklet (YoDCA).

Winterbottom A, Mooney A, Russon L, Hipkiss V, Williams R, Ziegler L, Finderup, J, Bekker HL. 2020. (Accessed via [kidneyresearchyorkshire.org.uk](http://kidneyresearchyorkshire.org.uk))

## Studies carried out to develop the decision aid booklet

Winterbottom A, Bekker HL, Russon L, Hipkiss V, Ziegler L, Williams R, Mooney A.

**Dialysis versus Conservative Care Decision Aid: study protocol.** Journal of Kidney Care 2018; 3:3:179-185

Winterbottom A, Mooney A, Russon L, Hipkiss V, Williams R, Ziegler L, Bekker HL. **Critical review of leaflets about conservative management used in UK renal services.** Journal of Renal Care 2020 Apr 8. doi: 10.1111/jorc.12327.

Winterbottom A, Mooney A, Russon L, Hipkiss V, Ziegler L, Williams R, Finderup J, Bekker HL. **Chronic Kidney Disease Pathways, Options and Decisions (CKD-POD): An Environmental Scan of International Patient Decision Aids (PtDA)**, Nephrology, Dialysis & Transplantation, accepted May 2020.

Winterbottom A, Mooney A, Russon L, Hipkiss V, Ziegler L, Williams R, Finderup J, Bekker HL. **Development of the Conservative Care and Dialysis Patient Decision Aid for Established Kidney Disease (EKD) education: Patient and Professional Views.** In preparation 2020.

© University of Leeds, Leeds UK (2020)

Authors: Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) study team:  
Winterbottom, Mooney, Russon, Hipkiss, Williams, Ziegler, Finderup, Bekker

Produced by: Medical Illustration Services • MID code: 20200514\_008/NR

LN004884 1st edition (Ver 1)

Publication date: 07/2020

Review date: 01/2022