

[FRONT COVER]

**Kidney Supportive Care - a guide
for patients and families**

**Leaflet 1:
Making your treatment decision**

[INSIDE FRONT COVER]

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1. Introduction

What is the aim of this booklet?

The aim of this booklet is to explain the treatment option for kidney disease called renal supportive care. Please take time to read this booklet and feel free to ask questions at your clinic appointments and share the booklet with family and friends.

Why have I been given this booklet?

You have been given this booklet for one of two reasons:

1. You are aware that you have kidney failure and you are trying to decide which future treatment might be right for you.

- You may be thinking about your choices for future care and want to know more about the supportive care (non-dialysis) option. If this is the case, you may find information about kidney treatment choices contained in this booklet particularly helpful.



For more information about alternative dialysis options please **ask your kidney team.**

2. You have already investigated treatment options and are comfortable that the supportive care (non-dialysis) option is right for you.

- Although you may have considered other options in the past, you now feel comfortable that this is the right treatment for you. If this is the case then we hope you will find this booklet useful and that it helps to guide you and those important to you through your future care.

KEY POINTS

You have been given this booklet because you have significant kidney disease

In the future you may choose to replace your kidney function with dialysis or to follow a tablet based pathway without dialysis (supportive care)

This booklet is designed to help you think about which treatment might be best for you

2. Thinking about your treatment choices

Why am I being asked to think about my future kidney treatment choices?

This is because your blood tests now show that you have less than 20% of your kidney function remaining. This means you have significant kidney problems. We want to give you the time to think about what type of treatment might be right for you in the future, if your kidney function continues to get worse.

You may choose to replace your kidney function by starting dialysis (kidney replacement treatment). Dialysis typically starts when you have about 10% of your kidney function remaining. Alternatively, you may feel that this is not the right treatment for you and that a supportive care (non-dialysis) option may be a better choice.

In order to give you time to think about the right decision for you, we are introducing your options now. This booklet is about the treatment option called supportive care.

What is supportive care?

Kidney supportive care (sometimes called conservative care) is an active form of treatment provided by your kidney team. It focuses on maintaining a good quality of life that is right for you but it never replaces your kidney function as dialysis does. ~~This means you choose to never have dialysis, but there is a focus on maintaining a good quality of life.~~ This is done by:

1. **Protecting your kidneys and keeping them working as well as possible for as long as possible.**

Maintaining low but adequate kidney function for as long as possible through regular reviews with you and your family or carers can be really helpful. These reviews can be either in the kidney clinic, or sometimes at home.

Many people provided with good care can be reasonably well for some time even with a kidney function below 10%. About half of the people who choose supportive care will eventually die due to kidney failure. The other half of people will find that they die for other reasons not related to their kidneys.

2. Controlling symptoms that may develop as your kidney function declines.

Medication, dietary and fluid changes, and some lifestyle changes can reduce symptoms.

You can read more about symptom control in [leaflet Z](#).

3. Supporting you, your family and carers to focus on the things you would like to achieve and prioritise

We can help you to do this through planning and communication, and minimise the time you spend in hospital.

4. Planning for the future whilst you are relatively well and can think about what you would like to happen in the later part of your life.

This allows you to think about where you want to be looked after, your wishes and preferences around medical treatment and care and what might or might not be right for you in the future. You might find it helpful to read [leaflet Y](#).

5. Providing you with a person-centred care approach which may include medical, social, psychological, financial and spiritual support.

6. Involving community nursing and medical support in your care

This allows us to optimise your comfort and dignity in later life. If for example, it is important to you to remain at home in the last days of life, then we can help support this. Please see [leaflet X](#).



Supportive care is about being in control of your treatment decisions with **support from your kidney team**.

You will be able to involve family and friends in those decisions if you want to.

Remember that different treatments are right for different patients - there is no “right” treatment - there is just the best treatment for you.

KEY POINTS

Supportive care is a very active form of kidney care but it never involves replacing your kidney function

3. Doesn't everyone just need to do dialysis?

No-one needs to do dialysis– you always have a choice. Making that choice involves thinking about the alternative treatments

Let's start by revisiting what dialysis involves. There are two types of dialysis:

Haemodialysis (blood dialysis): Blood is removed from your body, and is cleaned of toxins and excess fluid.

Peritoneal dialysis (tummy dialysis): A permanent tube is placed in your tummy and special fluids are used to remove toxins and excess fluid from your body.

Where does each type of dialysis treatment take place and what does it involve?

Haemodialysis

In haemodialysis you would attend a hospital or community dialysis unit three days per week for treatment.

You would be connected to a machine by a tube from your body which washes your blood for approximately 3.5 to 4 hours per session. You would be sitting in the same place for several hours at a time.

You would have a small operation to place a tube in your neck or create a special blood vessel in your arm (fistula) to allow us to clean your blood.

You may feel this commitment is too great or you may feel you would enjoy the social company of regular haemodialysis sessions.

Questions you might find helpful if you are thinking about haemodialysis

- Do I find it easy to leave my house - how would I find it going to and from dialysis 3 times per week?
- How far is my local dialysis unit from my home?
- How do I feel about spending lots of time at treatment sessions every week?
- What might I be able to do with that time if I did not dialysis?

Haemodialysis

Haemodialysis can be a good treatment but it is a big commitment



312

Journeys to and from
dialysis **per year**



3-4.5

Average **hours per session**



3

Treatment sessions
per week



Some people take
**several hours to
recover** after
haemodialysis



Haemodialysis is a
long term treatment



Haemodialysis involves a
small operation

Peritoneal dialysis

Peritoneal dialysis would be carried out by you in your own home. You would do dialysis treatment between 5-7 days a week.

You would use bags of fluid drained into the abdominal (tummy) cavity up to four times a day via a tube that is placed permanently into your abdomen.

For peritoneal dialysis you would have a small operation to place a tube in your abdominal cavity which then stays there.

Peritoneal dialysis can work really well if you want to stay at home and can give you a lot of independence and freedom.

However, this treatment does involve having medical equipment in your home and learning to do at least some of your own dialysis treatment. Even though dialysis takes place at home it requires some time commitment. It does not tend to work well if you struggle to move around or if you have had significant abdominal surgery in the past.

Although your treatment is done at home, you will need to come to hospital appointment about every 8 weeks to be reviewed and have blood tests.



You may want to **ask your kidney team** whether you could be considered for home peritoneal dialysis or not as this may help you decide the right treatment for you.

Questions you might find helpful if you are thinking about peritoneal dialysis

- Is it possible for me to do tummy dialysis?
- Do I want to do my own dialysis?
- Do I want to have medical equipment in my home?
- Do I want to do a dialysis treatment every day?

KEY POINTS

You have a choice of kidney treatment

Dialysis treatment can be good but it may not help everyone

Dialysis treatment can be good but requires a lot of time, commitment and effort

Peritoneal dialysis

Peritoneal dialysis can be a good treatment but it is a big commitment



Can be done
at home



Can take up to
10 hours at night
or **4 x a day**



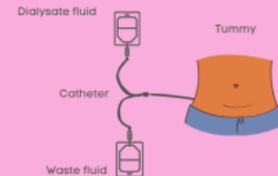
Peritoneal dialysis
takes place
5-7 days a week



Is a
long term treatment



Requires an operation
to insert the
dialysis through
the **tummy**



**Diagram of
peritoneal dialysis**

4. Why might it be good to consider supportive care?

It is natural to assume that if a treatment like dialysis is available, it must be of benefit to you and that it will make you live longer and feel better.

Although many patients do benefit from dialysis treatment this is not always the case for every patient.

This may be true if you have additional health problems such as diabetes, heart disease, dementia, or if you have suffered a stroke.

Every patient starting dialysis treatment is different but dialysis cannot extend any patient's life forever.

Patients with severely impaired kidney function have a shorter life span than people of the same age who do not have kidney problems.

Each patient is an individual but you may find it helpful to think about the following:

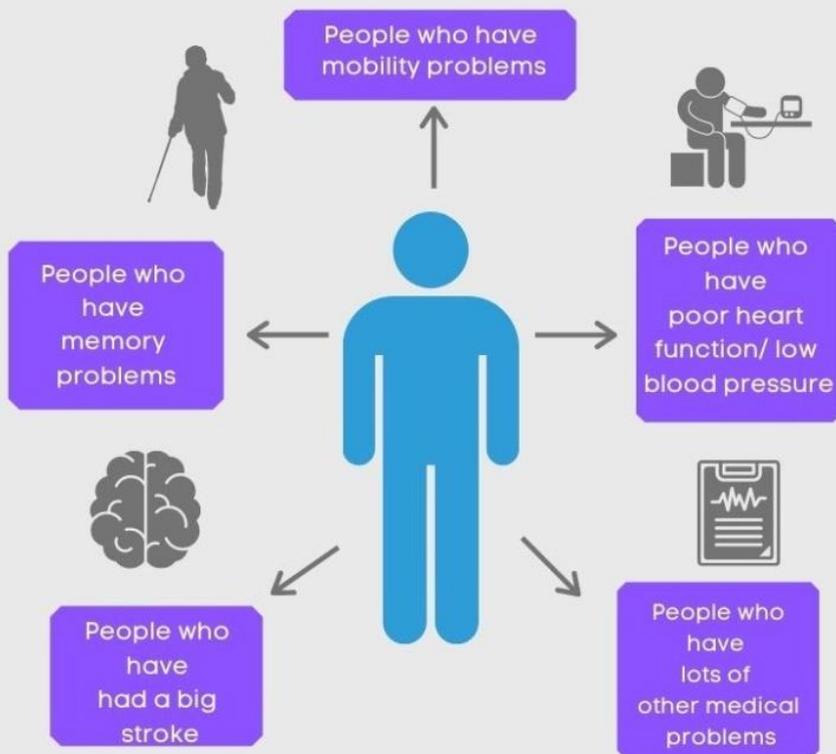
- Dialysis generally extends younger patients lives, but this may not always be the case for patients who are older. In particular if you are over 80 it is not yet known whether you will live longer with or without dialysis
- People who have lots of additional medical problems (especially if they have had heart attacks or strokes) do less well on dialysis than those who have not suffered these problems. This could mean they may not live longer with dialysis treatment
- Patients who start dialysis from a nursing home may not live longer with dialysis treatment
- Patients who need lots of help at home (for instance with washing and dressing) or who spend much of their time in bed may not live longer with dialysis treatment.

Dialysis can be a demanding treatment and you may find that your quality of life is better without dialysis treatment.



Please **talk to your kidney team** about how they think you might find dialysis treatment. You might want to ask them if they think it would be likely to extend your life.

People who might find dialysis hard



5. How do I know which option is right for me?

Here are some more questions you may wish to think about when deciding whether dialysis or supportive care is the right treatment for you.

If you are still considering the dialysis option make sure you ask your kidney team to give you information leaflets about this option as well.

Will dialysis help my symptoms and quality of life?

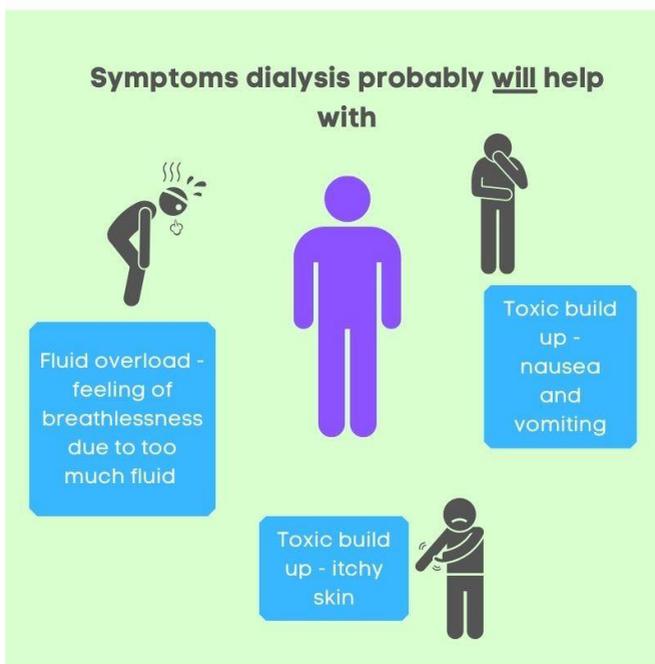
Research studies suggest that dialysis can help with some symptoms caused by kidney toxins that build up as our kidneys fail. These might include breathlessness if you have fluid problems or nausea. Patients on dialysis often require tablets to help with other kidney related symptoms such as itchiness or restless legs (jumpy legs).

If you have symptoms that are not related to your poor kidney function such as memory problems, difficulties with mobility, difficulties with continence, or pain related to arthritis, then dialysis will probably not help these and may make them worse.

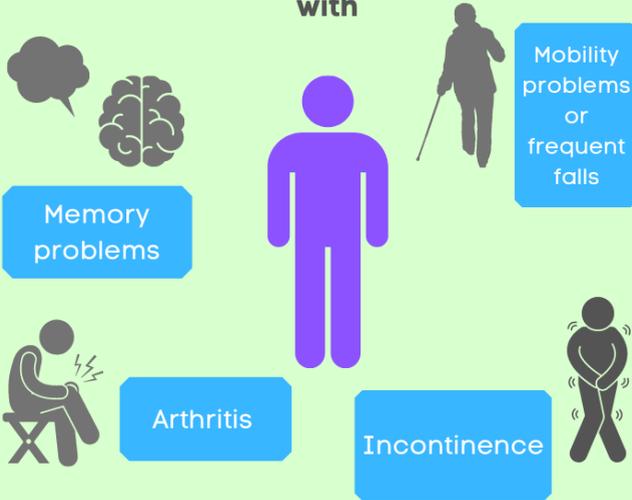
Can you help me with symptoms that are not caused by my kidney problem?

If we identify symptoms that are not related to your kidney problems then we or your GP can help, for example by:

- Referring you to a memory clinic if you have memory difficulties
- Arranging physiotherapy for mobility problems or frequent falls
- Arranging pain control or a referral to a joint specialist if you have joint pains



Symptoms dialysis probably won't help with



Support services available



You might want to **talk to your kidney team** about which of your symptoms dialysis will help with.

Would dialysis affect my normal life?

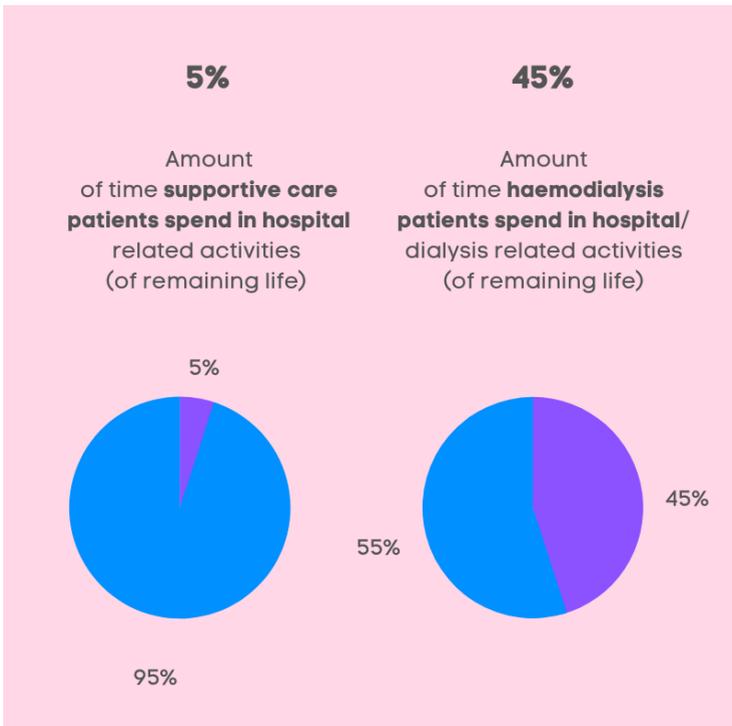
Some patients find that their quality of life gets worse in the three months after starting dialysis so it is important to consider if you feel a visit to a treatment centre three times per week might impact on your quality of life.

Alternatively you may feel that a regular trip outside your home and getting to know other patients who dialyse with you at the dialysis unit might be an attraction. Thinking about this might help you decide which type of treatment might be right for you.

Peritoneal dialysis allows you to do your treatment at home but still takes quite a lot of time and involves having medical equipment in your house. Thinking about this might help you decide which type of treatment might be right for you.

How much time would the supportive care pathway take compared to dialysis treatment?

If you choose supportive care you will probably spend a lot less time doing treatment than if you choose dialysis.



If you choose supportive care you will probably spend about 5% of your remaining life in treatment related activities (e.g. hospital appointments).

If you choose haemodialysis treatment you may spend over 45% of your remaining daytime life in hospital or dialysis related activities. This is almost half of your time. Time spent in hospital could be related to dialysis activities, or other hospital admissions either for kidney related problems, or related to another health problem you may have.

Not having dialysis can free up time to pursue interests or see family and friends. It means spending much less time in hospital and may allow you to have more control over the later part of your life.

You might want to think about how much treatment-free time you would like.

How much travelling will I need to do if I opt for supportive care?

If you chose the supportive care pathway you will do less travelling for medical care in comparison to dialysis patients. Typically if you opt for supportive care you might be seen by your kidney team every 4 to 12 weeks and can often be seen close to home. Some services are able to offer a home visiting service for you if you are very frail.

Do I need an operation if I have supportive care treatment?

If you follow the supportive care pathway you do not need to have any operations.

Is traveling to other parts of the world an important part of my life?



It is possible to organise both haemodialysis sessions and peritoneal dialysis in many but not all other parts of the world, but it takes quite a lot of planning. In addition, any trips may need to be quite short (2 - 4 weeks)

If you like to travel abroad frequently (for instance to see family in the later part of your life) or to spend part of your year in another part of the world, ask your clinical team for more information as sometimes the supportive care pathway can allow travel that might be very difficult or impossible with dialysis.

KEY POINTS

Not all patients benefit from dialysis treatment

For some patients dialysis:

- Does not make them live longer
- Does not make them feel better
- Does take time away from doing things that are more important to them

You have a choice about whether you want to do dialysis treatment or not

How many people choose the supportive care pathway?

Up to about 20% of people whose kidney function has declined to less than 20% choose a supportive kidney care option.

Supportive care



Up to **20%** of people whose kidney function has declined to less than 20% **choose** to follow a **supportive kidney care pathway**

Who will care for me if I choose a kidney supportive care treatment option?

If you choose supportive care you will be cared for by a team of health care workers. This will include specialist kidney nurses, kidney doctors, dietitians, pharmacists, social workers and counsellors. Your GP and district nurses may also be very involved in your care. We know that it is important to have on-going care from a team that you know and trust, and who are fully aware of previous decisions you have made with respect to your healthcare.



Kidney doctors, pharmacists,
kidney nurses, physiotherapists and dietitians are just
some of the people who be a part of your care team

Where can I be seen on the kidney supportive care pathway?

Most kidney teams run a supportive care clinic at their main hospital but also have outreach clinics at other hospitals in the region. It may be possible to see you at an outreach clinic which is closer to home, or even at home if this is required. The home service is usually for people who are very unwell, have a lot of symptoms and who find it difficult to attend a clinic appointment.

You will be seen every 4 to 12 weeks depending on your level of kidney function and how you are feeling. Your treatment will be ongoing but rather than attending for dialysis, we will focus on symptom control and quality of life.

What will happen at the end of my life if I choose supportive care?

We know that planning for the care you will receive right at the end of your life is very important. Many patients value the chance to think about how and where they would want to be looked after at this stage. We have therefore written an accompanying leaflet to help you with this

Please ask a member of your kidney care team for a copy of **leaflet W.**

What are the different phases of the kidney supportive care pathway?

When we see you in clinic we will go through your latest blood results with you and check how you are feeling. Seeing you in clinic and monitoring your blood tests will give us an idea of how quickly your kidney function is changing. This will help us to plan your future care.

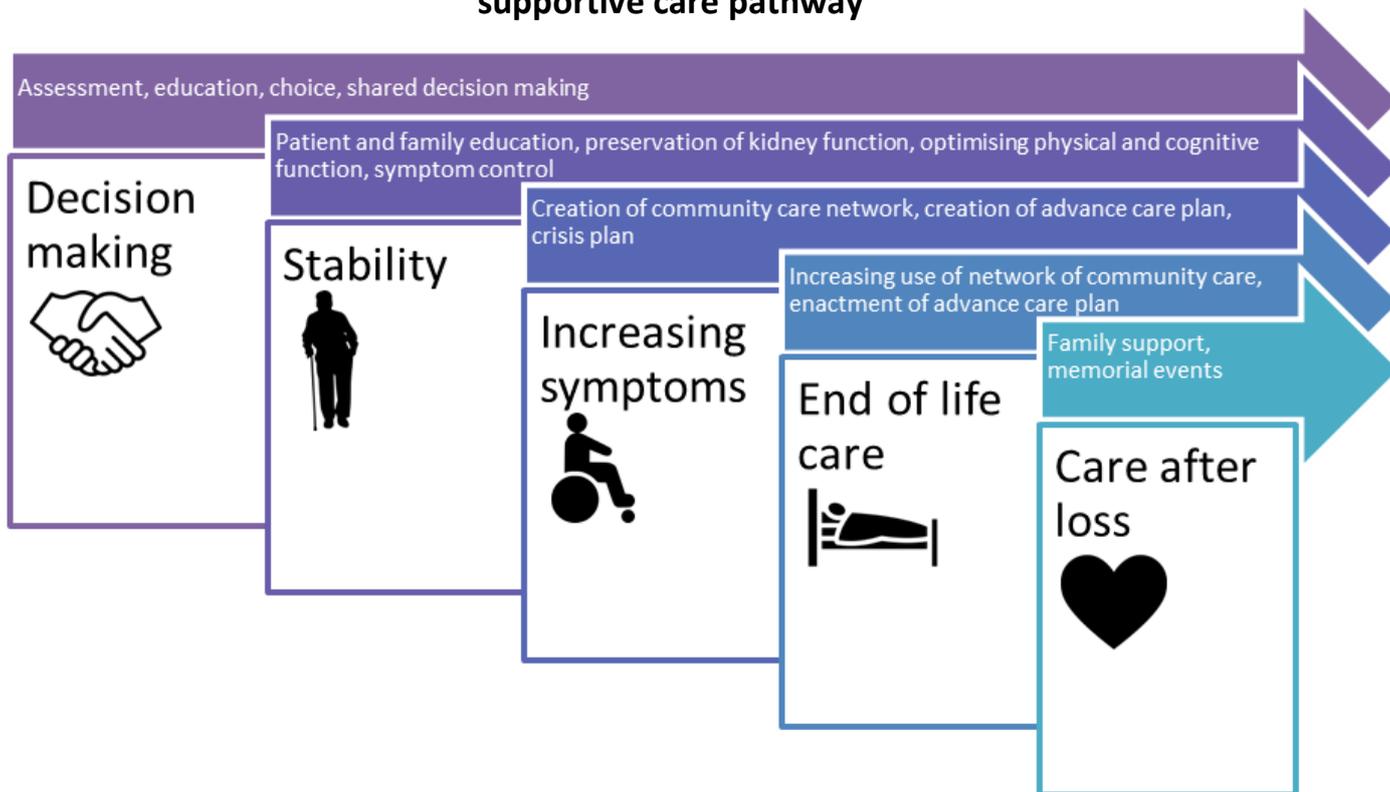
When your kidneys are functioning between 20% and 10% of normal we do all that we can to preserve your remaining kidney function and keep you feeling as well as we can. We also spend time improving symptoms by using medication, and give you advice about your diet and how much fluid you are drinking. You can learn more about this in the accompanying [leaflet V](#).

When your kidney function declines to less than 10% we start concentrating on making plans for your future care to ensure your wishes and preferences are taken into account and that we know what you would and would not like if you became more unwell. We call this advanced care planning and you can read more about it in the accompanying [leaflet U](#).

As your kidney function declines more, or if you become troubled by more complex symptoms we can refer you to the community palliative care team, with your

consent. The local palliative care team can provide additional local support.

This diagram might help you to understand the different phases of the supportive care pathway



6. Making your treatment decision

The tables below summarise the key features of both dialysis and the supportive care treatment options – they may help you to decide what is right for you.

Question	Haemodialysis	Peritoneal dialysis	Supportive care
Does this treatment replace my own kidney function?	Yes	Yes	No
Where does this treatment take place?	Usually in a hospital or community treatment centre	In your own home	In your own home
Who does the treatment?	Staff in the dialysis in it	You will do your own treatment supported by hospital staff if needed	You will do your own treatment

Question	Haemodialysis	Peritoneal dialysis	Supportive care
How long does each treatment take?	About 3.5 to 4 hours of treatment plus time to travel	You will need to set aside about 40 minutes between 2 and 4 times per day to do this treatment.	There is no kidney replacement treatment to do if you choose supportive care
Do I need to have an operation for this treatment?	Yes	Yes	No
Do I need complex equipment in my home if I do this treatment?	Only if you chose to do your haemodialysis at home	This treatment does come with additional equipment in your home	There is no additional equipment for this treatment

Question	Haemodialysis	Peritoneal dialysis	Supportive care
<p>Is there anyone who cannot have this treatment</p>	<p>People with very poor heart function may struggle with this treatment.</p> <p>People with lots of other medical problems may struggle with this treatment.</p>	<p>People who have had big tummy operations may not be able to do this treatment.</p> <p>People with lots of other medical problems may struggle with this treatment.</p>	<p>It would be unusual for people who are considering kidney transplants to consider this treatment</p>

Who are the team who will look after me?	Nurses, doctors and other members of the team at the dialysis unit.	Nurses, doctors and other members of the team at the kidney unit.	Nurses, doctors and other members of the team at the kidney unit. Your GP and other community teams.
How many days a week do I need to do the kidney replacement treatment?	3 days per week	Between 5 and 7 days per week	There is no kidney replacement treatment if you choose supportive care

Question	Haemodialysis	Peritoneal dialysis	Supportive care
How often will I need to come to specialist appointments?	About every three months	About every three months	Initially every three months though we may see you more often if you would benefit

Weighing up your decisions

Alternatively you might want to think about the decision as a balance - depending on the things that are important to you it might tip either toward supportive care or towards dialysis.

You might find **dialysis** is better for you if...

- It is likely dialysis will **extend your life**
- You enjoy the **sociability** of unit



- You don't like being at **home all day**
- You have **lots of symptoms**, related to kidney problems
- Your remaining **kidney function is falling quickly**

You might find **supportive care** is better for you if...



- You want more **time for hobbies and family**
- You want **fewer hospital visits**
- **You like to travel**
- Your remaining **kidney function is declining slowly**
- You find it **hard to leave home**
- You **don't want any more DPs/ procedures**
- You have **multiple problems not helped by dialysis** e.g. frailty
- You suffer from **memory loss**

Questions you might find helpful when you are thinking about what treatment might be right for you

- How complicated a treatment do I want at this time in my life?
- How do I feel about leaving my house several times a week for kidney treatment?
- Am I mostly focused on quality of life or would I be prepared to do complex treatment if there was a possibility it would make me live longer?
- How many of my symptoms will be helped by taking the dialysis treatment choice?

Sometimes making this decision can feel really difficult and scary.

Take your time, talk to family and friends and feel free to **ask your kidney care team** lots of questions.

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CONTACT DETAILS, ORGANISATION ETC