Kidney Supportive Care - a guide for patients and families

Making your treatment decision

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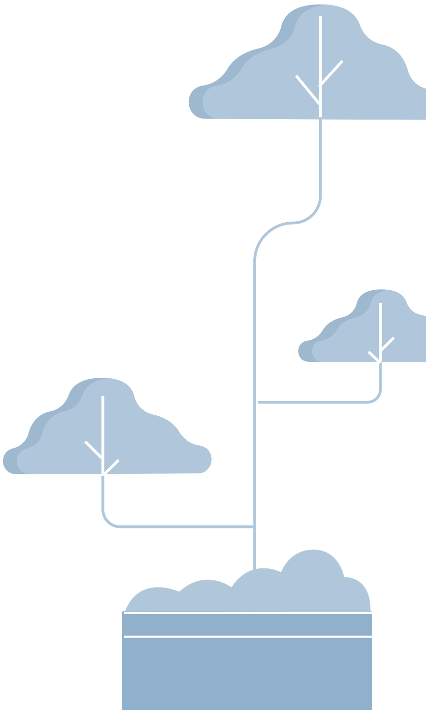
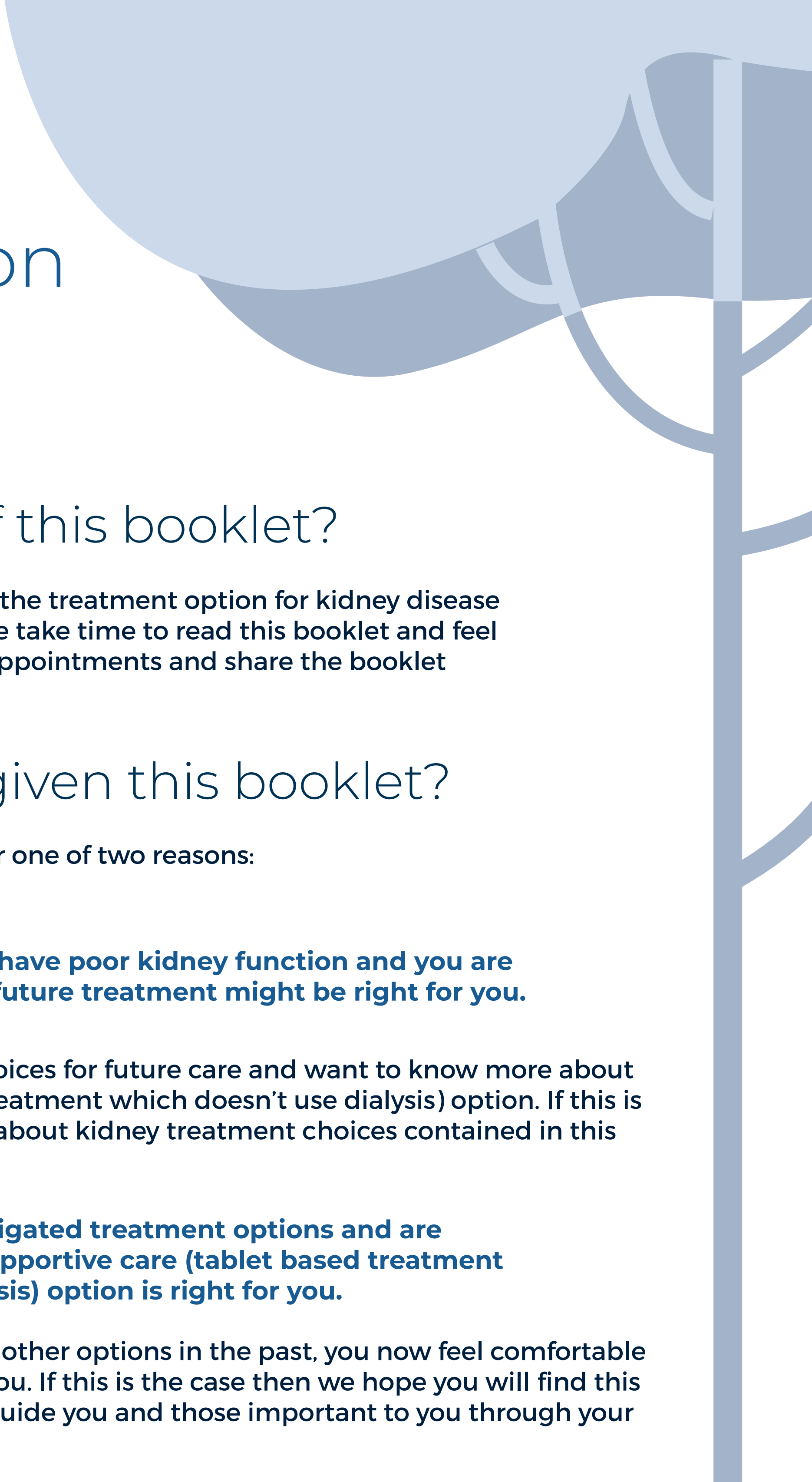




1: Introduction

What is the aim of this booklet?

The aim of this booklet is to explain the treatment option for kidney disease called kidney 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 poor kidney function 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 (tablet based treatment which doesn't use dialysis) option. If this is the case, you may find information about kidney treatment choices contained in this booklet particularly helpful.

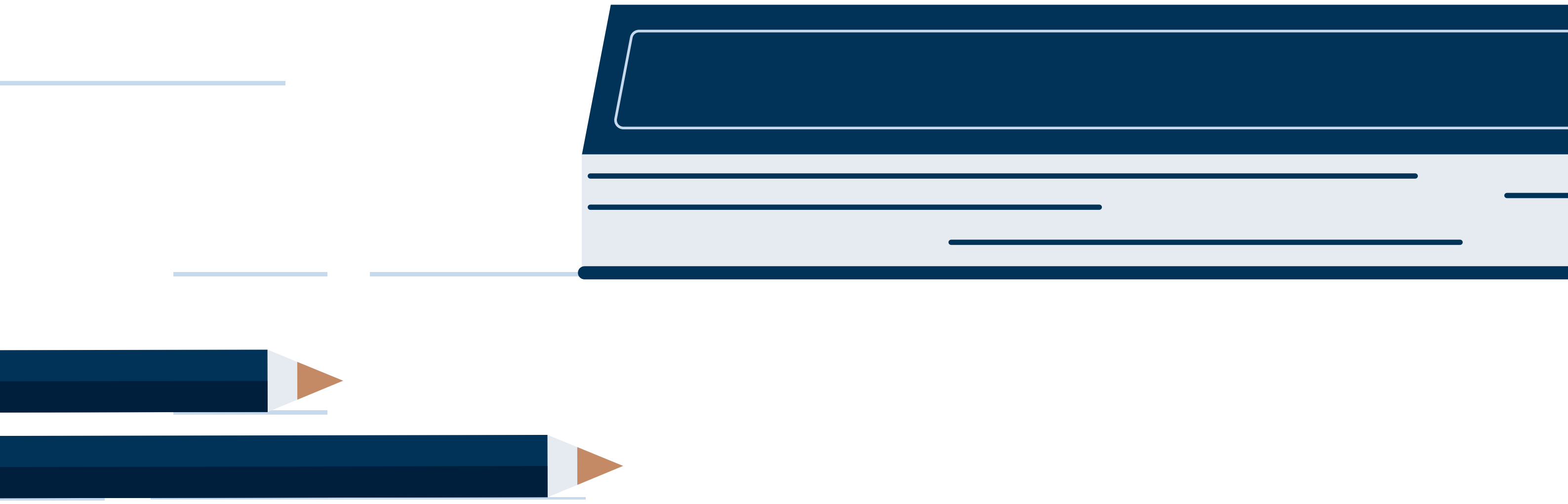
2 **You have already investigated treatment options and are comfortable that the supportive care (tablet based treatment which doesn't use dialysis) option is right for you.**

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.

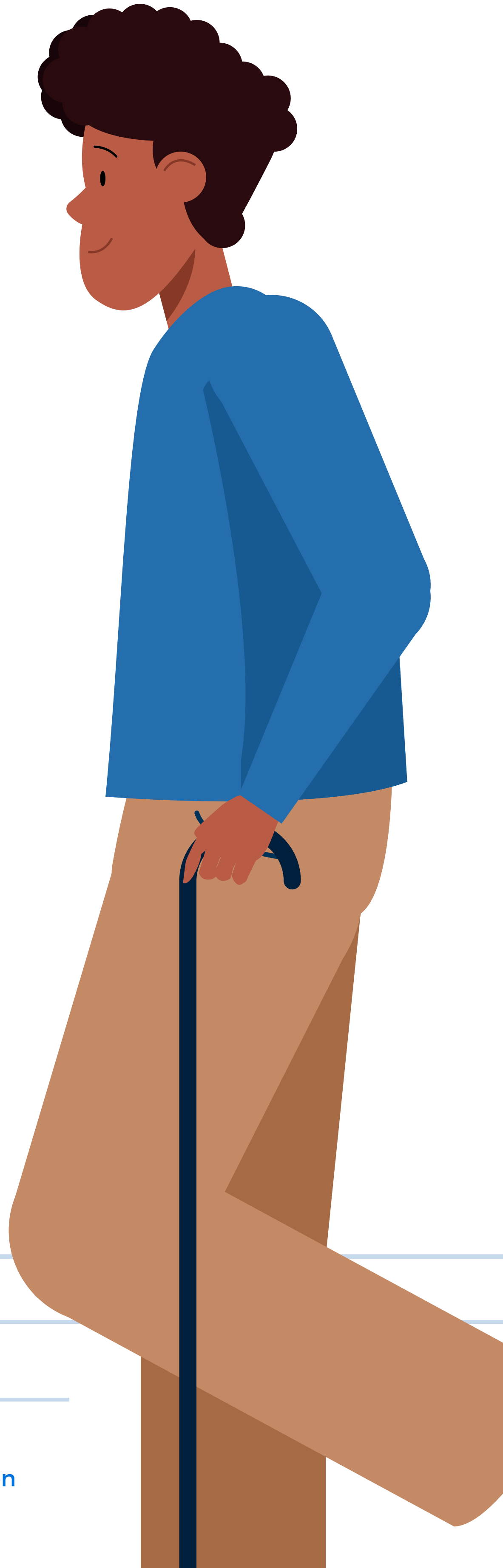
For more information about dialysis options please ask your kidney team.

Key Points

- You have been given this booklet because you have significant kidney disease.
- In the future you may choose to follow a table-based treatment without dialysis (supportive care) or to replace your kidney function with dialysis.
- This booklet is designed to help you think about which treatment might be best for you.
- It will be your choice which type of treatment you have.



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 (tablet based treatment which doesn't use dialysis) option may be a better choice.

Your decision on treatment may also change over time, and it important that you discuss this with your kidney team. This booklet is about the treatment option called supportive care.

What is supportive care?

Kidney supportive care, or enhanced supportive 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 is done by:

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

Maintaining your kidney function for as long as possible through regular reviews with you and your family or carers can be really helpful. We can help your kidneys by treating your blood pressure or diabetes and making sure you are not on any tablets that are bad for your kidneys. These reviews may be in a kidney clinic. Some teams are also able to provide these visits at your home.

Many people provided with good care can remain well for some time with very low kidney function even if they do not start dialysis treatment.

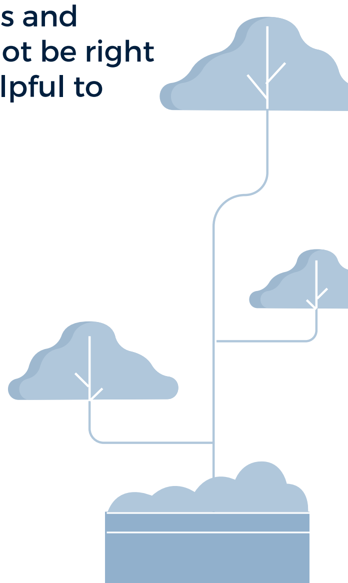
2 Controlling symptoms that may develop as your kidney function declines.

Medication, dietary and some lifestyle changes can help treat symptoms that develop as a result of your kidney disease[1]. Symptoms you may experience include leg swelling, breathlessness, nausea, itching and restless legs.

Please ask your doctor or nurse for more information on how to improve your symptoms.

3 Planning for the future whilst you are relatively well and can think about what care you would like.

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. We call this advance care planning. You might find it helpful to talk to your doctor or nurse to find out more.



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

This includes identifying any of your symptoms or other problems that are not the result of your kidney problem. This includes symptoms like frequent falls or memory difficulties. We can then signpost or refer you to services which can help you with these other problems.

5 Maximising community services – finding ways to keep you out of hospital.

Your kidney team will help to find the right services to ensure you remain well and have support at home. This will help you have good management of any symptoms and the right comfort and dignity in later life. If for example, it is important to you to remain at home if you become very unwell or in the last days of life, then we can help support this.

Remember that different treatments may be better for different patients – we want to work together to arrange 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

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

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

3: I had not realised there was a choice about dialysis

Having dialysis is always a choice. You do not have to have dialysis.

Making that choice involves thinking about the other treatments and understanding the pros and cons of the different choices.

Let's start by revisiting what dialysis involves. There are two types of dialysis: haemodialysis (blood dialysis) and peritoneal dialysis (tummy dialysis). Both dialysis types are long term treatments which for older patients usually continue for the rest of their life.

Haemodialysis (blood dialysis):

Blood is removed from your body, and is cleaned of toxins and excess fluid before being returned to your body.

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.

What are the other treatment options?

Haemodialysis

Haemodialysis normally involves attending a hospital or community dialysis unit three days per week for treatment. Sometimes with training it may also be possible to do this treatment at home.

You will be connected to the dialysis machine through a tube that has access to your blood. This is either a blood vessel in the arm (fistula) or a small catheter in your chest, which will require a small operation. The dialysis machine then washes your blood for approximately 3.5 to 4 hours per session. You will be sitting in the same place for several hours at a time.

You also have to spend some time connecting and disconnecting from the dialysis machine and travelling to and from the dialysis unit so the whole "treatment" can take 6 or 7 hours per treatment session. Haemodialysis is long term treatment so for most patients, once started, it continues for the rest of their lives.

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 is carried out by you in your own home with support from the kidney team. You do the dialysis treatment between 5 to 7 days a week.

Bags of fluid are drained into the abdominal (tummy) cavity between two and four times a day via a tube that is placed permanently into your tummy. Each bag would stay in your tummy for between 3 and 5 hours at a time. Each change of fluid bag takes about 25 minutes.

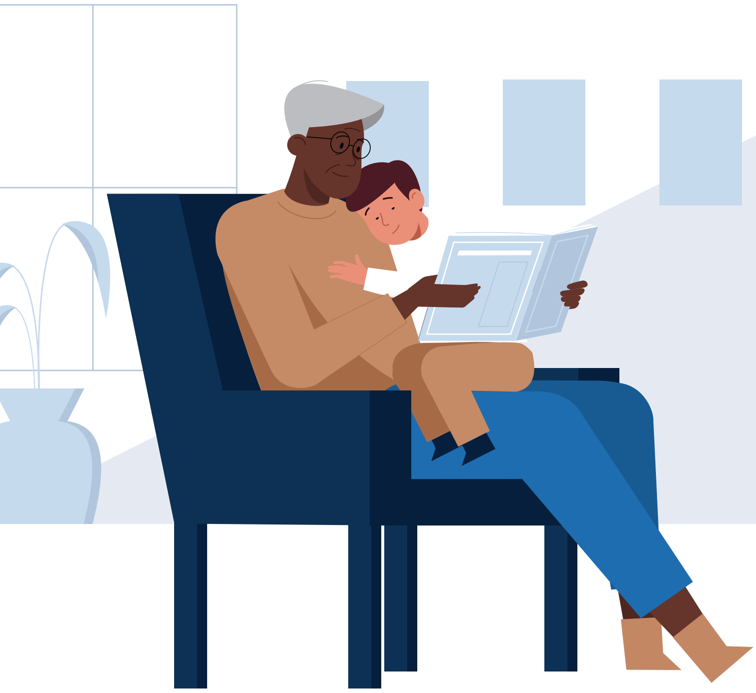
Alternatively you might be able to do overnight tummy dialysis - this means you would be attached to a machine for between 7 and 9 hours each night to put the fluids in and out of your tummy. The machine is set up before you go to bed so you can sleep whilst it is working.

For peritoneal dialysis you need a small operation to place a tube in your tummy which then stays there.

Peritoneal dialysis can work well if you want to stay at home and can help you to maintain your independence and freedom. Once again peritoneal dialysis is generally long term treatment once started.

This treatment involves having space at home for the equipment and learning to do at least some of the dialysis yourself. Even though dialysis takes place at home it requires a time commitment to carry it out. It does not tend to work well if you struggle to move around or if you have had significant abdominal surgery in the past. It may also be difficult with other medical problems for example if you have arthritis in the hands.

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



Not everyone is able to do peritoneal dialysis treatment. 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.

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 4x a day**

Peritoneal dialysis takes place **5-7 days a week**

Peritoneal dialysis is a
long term treatment

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

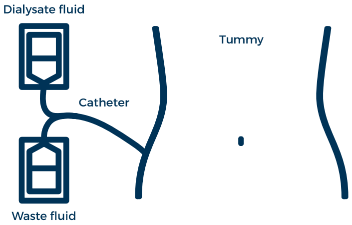


Diagram of peritoneal dialysis

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**
- **Supportive care can be a good alternative treatment to dialysis.**

4: Why should I 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 people do benefit from dialysis treatment this is not the case for everyone. This may be especially true if you have additional health problems such as diabetes, heart disease, dementia, or if you have suffered a stroke [2, 3, 4, 5, 6, 7].

Everyone starting dialysis treatment is different but dialysis cannot extend anyone's life forever.

People with severely impaired kidney function have a shorter life span than people of the same age who do not have kidney failure, whether they chose to have dialysis or supportive care [8, 9].

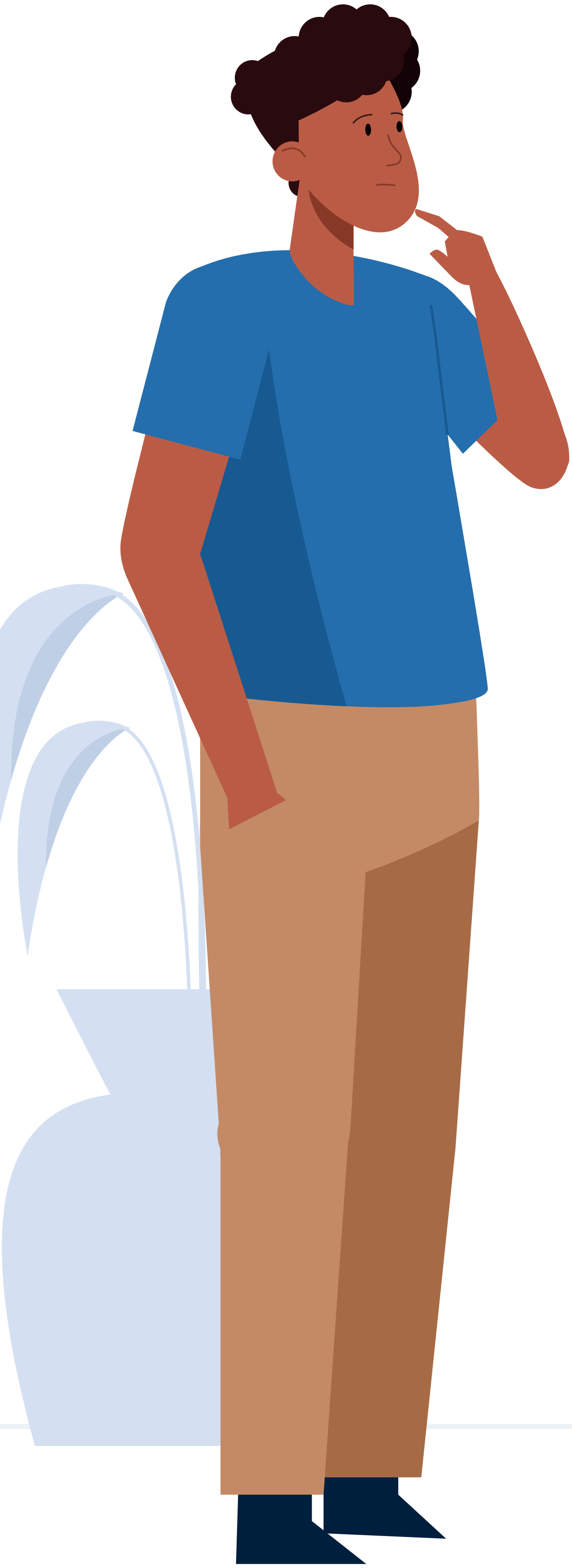
Dialysis can be a demanding treatment both physically and mentally and you may find that your quality of life is better without dialysis treatment [12, 13, 14].

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 expectancy.

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

- Dialysis generally extends the lives of younger people, but this may not always be the case for older people. In particular if you are over 80 it is not yet known whether you will always live longer with or without dialysis [10].
- 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 [6].
- People who start dialysis from a nursing home may not live longer with dialysis treatment [11].
- People who need lots of help at home (for instance with washing and dressing) or who spend much of their time in either a chair or bed may not live longer with dialysis treatment [10].

People who might find dialysis hard?



- People who have mobility problems
- People who have poor heart function/low blood pressure
- People who have lots of other medical problems
- People who have had a big stroke
- People who have memory problems

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?

We know that dialysis can help with some symptoms caused by kidney toxins that build up as our kidneys fail. These might include breathlessness or nausea.

Patients on dialysis often also require tablets to help with other kidney related symptoms such as itchiness or restless legs (jumpy legs).

On the supportive care pathway we use tablets, diet changes and life style advice alone to treat your kidney symptoms.

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, then dialysis will probably not help these.

How can I get help with symptoms that are not caused by my kidney problem?

If we or your GP identify symptoms that are not related to your kidney problems then we can help to manage this, 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

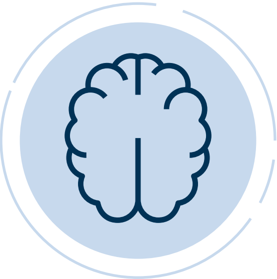
Symptoms dialysis probably **will** help with

Fluid overload feeling of breathlessness due to too much fluid

Toxin build up - itchy skin

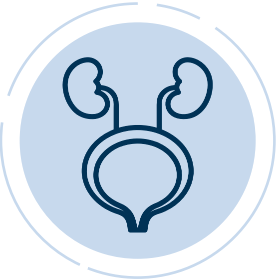
Toxin build up - nausea and vomiting

Symptoms dialysis probably **won't** help with



Memory problems

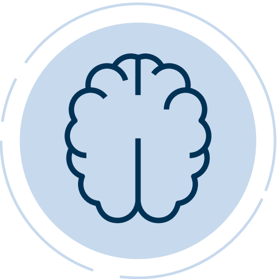
Pain



Leaky bladder

Mobility problems or frequent falls

Support services available include:



Memory clinic

Pain control & joint specialists

Continence services

Falls clinic

Would dialysis affect my normal life?

It is a big commitment to have dialysis. This can have a significant impact on normal life. Patients may find that their quality of life gets worse after starting dialysis [12, 13, 14, 15]. It is important to consider how dialysis might impact on your quality of life.

If you have haemodialysis you will have trips to hospital three times per week. This can have a significant impact on normal 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. Peritoneal dialysis allows you to do your treatment at home but still takes time and involves having medical equipment in your home.

Thinking about this might help you decide whether dialysis treatment might be right for you or whether supportive care might be a better option.

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

If you choose supportive care it is likely you will spend less time having treatment than if you choose dialysis.

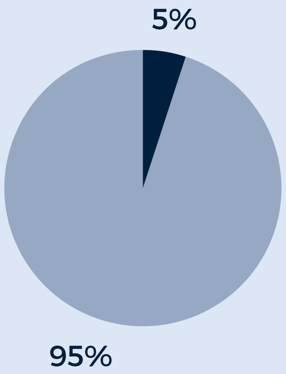
If you choose supportive care you will (probably) spend about 5% of your life in treatment related activities (e.g. hospital appointments).

If you choose haemodialysis treatment you may spend as much as 45% of your daytime life in hospital or dialysis related activities.

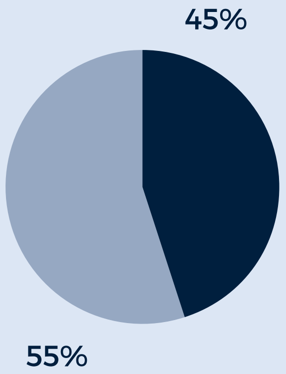
Time spent in hospital could be related to dialysis activities, or other hospital admissions either for kidney related problems, or related to another health problem you may have [14].

Not having dialysis can free up time to pursue interests or see family and friends.

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



5%
Amount of time supportive care patients spend in hospital related activities (of remaining life)



45%
Amount of time haemodialysis patients may spend in hospital/ dialysis related activities (of remaining life)

How much travelling will I need to do if I opt for supportive care and where will I be seen?

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 in hospital or at home, or by the community team or your GP every 4 to 12 weeks.

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 requires planning. In addition, any trips may need to be quite short (2 to 4 weeks)

If you like to travel abroad frequently (for instance to see family 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 everyone benefits from dialysis treatment

For some people 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?

Different kidney units look after different types of kidney patients so it is difficult to answer this question with an average number. Generally, somewhere between 10-25% of people with a GFR of less than 15 will chose supportive care in any kidney unit.

Around **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. The team may include specialist kidney nurses, kidney doctors, dietitians, pharmacists, social workers and counsellors. Alternatively your GP and district nurses or a care of the elderly team 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 dietiticians are just some of the people who be a part of your care team

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. This review will give us an idea of how quickly your kidney function is changing and help us to help you plan your future care.

When your kidneys are functioning at between 20% and 10% of normal we do all that we can to preserve your remaining kidney function for instance by treating your bloods pressure or treating any urine infections. We also spend time improving kidney symptoms by using medication, and give you advice about your diet and how much fluid you are drinking. Please ask your kidney team for more information. Finally we try to optimise your quality of life by referring you onto other specialist services for additional problems like heart failure, memory difficulties or frequent falls.

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 speak to your kidney team or your GP to find out more.

If your symptoms start to significantly impact on your life, we can refer you to the community palliative care team. They are based at your local hospice and often have lots of experience looking after kidney patients.

They can continue to support you at home or help with arrangements to transfer you to a hospice if you are reaching the last part of your life. If you reach the end of your life due to your kidney disease, this might not happen until you reach less than 5% of remaining kidney function.

Decision making

Assessment, education, choice, shared decision making

Stability

Patient and family education, preservation of kidney function, optimising physical and cognitive function, symptom control

Increasing symptoms

Creation of community care network, creation of advance care plan, crisis plan

End of life care

Increasing use of network of community care, enactment of advance care plan

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 unit	You will do your own treatment supported by hospital staff if needed	You will do your own treatment - eg you will take tablets to control your symptoms.
How long does each treatment take?	About 3.5 to 4 hours of treatment plus some waiting time and time to travel	You will need to set aside about 25-30 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?	No – most people do dialysis in a dialysis centre so the equipment is kept there	This treatment does come with additional equipment in your home	There is no additional equipment for this treatment

6: Making your treatment decision

Question	Haemodialysis	Peritoneal dialysis	Supportive care
Is there anyone who cannot have this treatment	People with very poor heart function may struggle with this treatment. People with lots of other medical problems may struggle with this treatment.	People who have had big tummy operations may not be able to do this treatment. People with lots of other medical problems may struggle with this treatment.	It would be unusual for people who are considering kidney transplants to consider this treatment
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
How often will I need to come to a clinic appointment with my kidney team?	About every three months	About every two months	Initially every three months though we or your GP may see you more often if you would benefit and also later in the pathway.

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 daunting.

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

What we CAN do with supportive care

Supportive care allows us to focus on your quality of life

- ✓ **It means spending less time in treatment**
- ✓ **And perhaps more time with family and friends**
- ✓ **It is also more likely to allow you to travel, if this is important to you**
- ✓ **It is a very active pathway, aiming to keep you as well as possible for as long as possible**
- ✓ **Not for everyone, but worth considering if you feel you have got to a point were quality of life is more important than complex medical treatments**
- ✓ **Worth considering if the majority of your symptoms are not related to your kidney condition**

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This booklet was created by the London Kidney Network Supportive Care Workstream. It is intented to be used to support conversations with your kidney doctors and nurses. The information in this leaflet doesn’t replace or superceed their advice which is specific to you.

If you have any questions, please talk to your doctor.

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