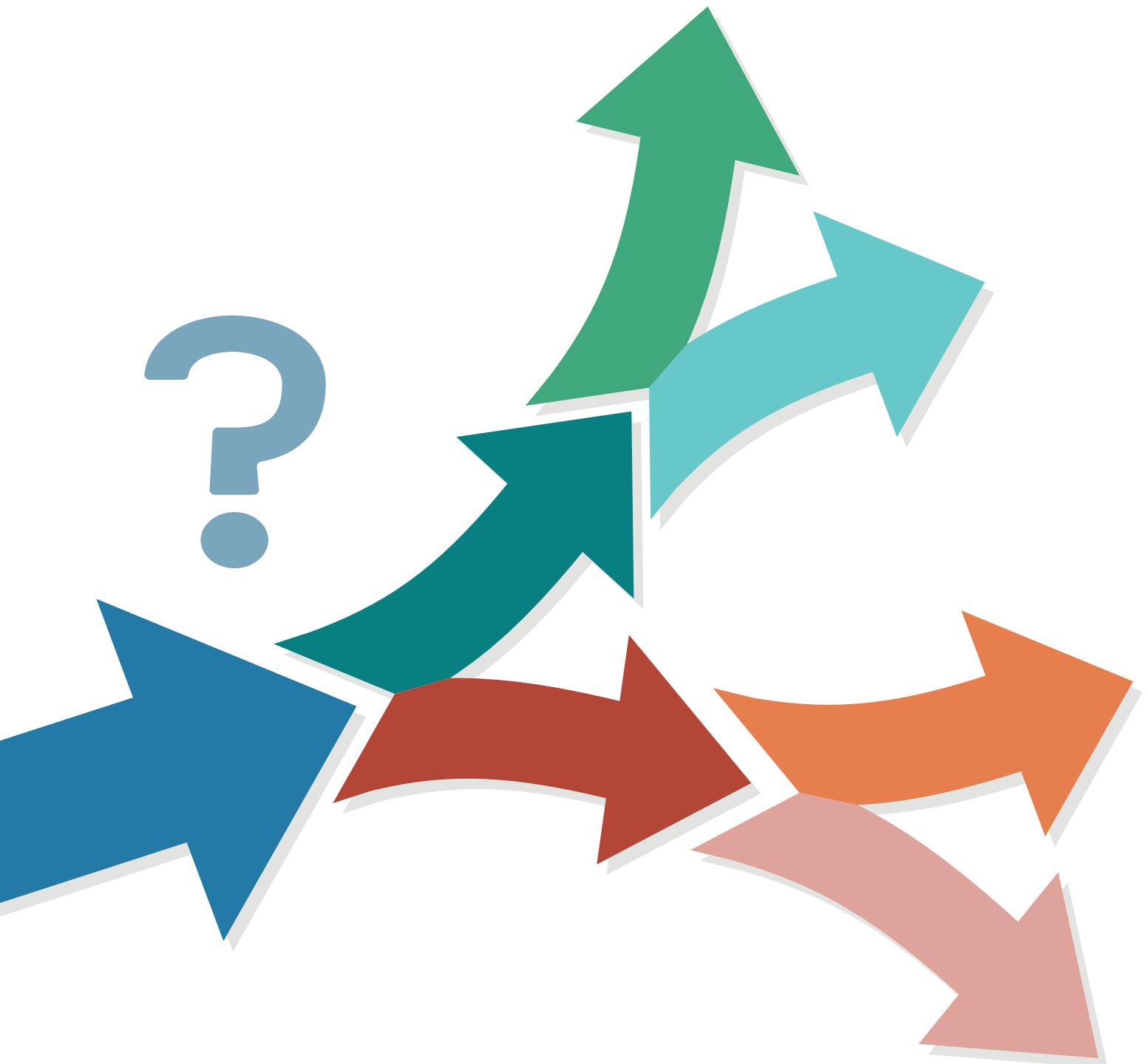


# Dialysis choice

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# Introduction

This decision aid is made for you, who have kidney failure and are in need of dialysis. You have to make a decision regarding the right mode of dialysis for you. The purpose of this decision aid is to involve you and your relatives in the decision-making regarding mode of dialysis to ensure you make the choice that best fits you and your life. In this decision aid we may introduce words that you are not familiar with or do not know. In the final part of this decision aid you find a short glossary explaining some of these words.

## Meetings regarding choice of dialysis mode

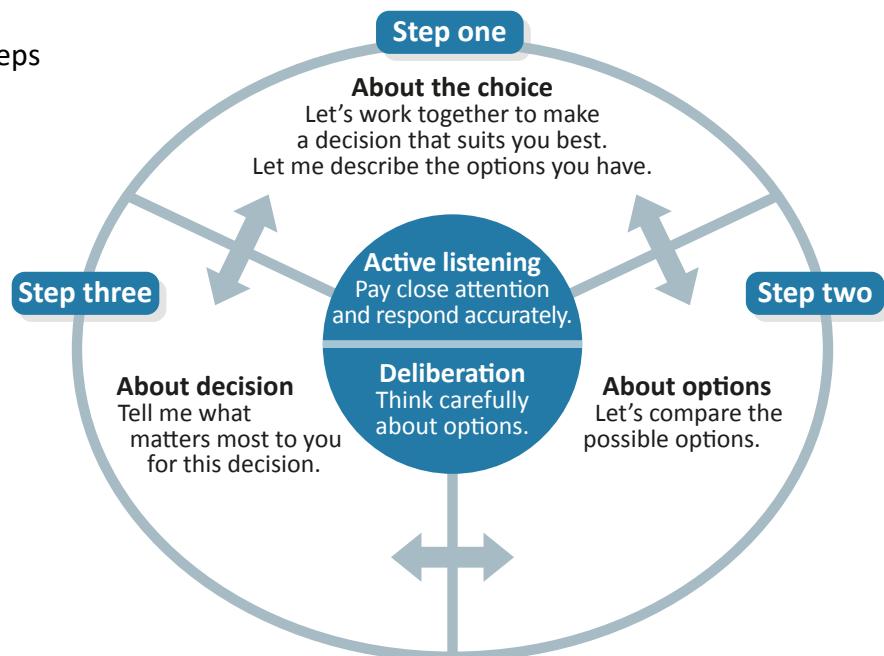
The healthcare professionals managing your condition have found out that you soon need to make a decision regarding your future mode of dialysis. A healthcare professional at the outpatient clinic will invite you and your relatives to individual meetings. The purpose of these meetings is that you, your relatives and the healthcare professional together make a decision on which dialysis mode would be the best fit for you.

The meetings involve three steps:

- Step one – about the choice
- Step two – about the options
- Step three – about the decision

Figure 1 shows an overview of the three steps. The exact number of meetings will depend on your needs. The meeting will always be organised and scheduled to fit your individual needs. Most patients are offered to join the *kidney school* before the meetings. The *kidney school* is an education programme for patients in the same situation as you, informing about kidney failure and the treatment opportunities. The teaching is carried out by healthcare professionals and patients together.

Figure 1: Overview of the three-steps



# Step one – about the choice

The purpose of Step one is to create an understanding of why a choice about dialysis mode has to be made and your options. The purpose is also to clarify which support you need to make a decision.

## **Why do I need to make a decision?**

You need to make a decision because you have kidney failure.

Kidney failure means that your kidneys are no longer able to sufficiently cleanse the blood and remove extra fluid from your body; you therefore need to cleanse your body in another way.

The outpatient clinic measures your kidneys' ability to cleanse the blood in your body; this is called eGFR. An eGFR below 10 ml/min is often the limit for needing dialysis and most patients have symptoms of kidney failure.

It differs from person to person when you reach this limit; maybe it will take weeks, months, and even years. Most often, your condition slowly deteriorates over months, but the deterioration will be faster if you for example get an infection.

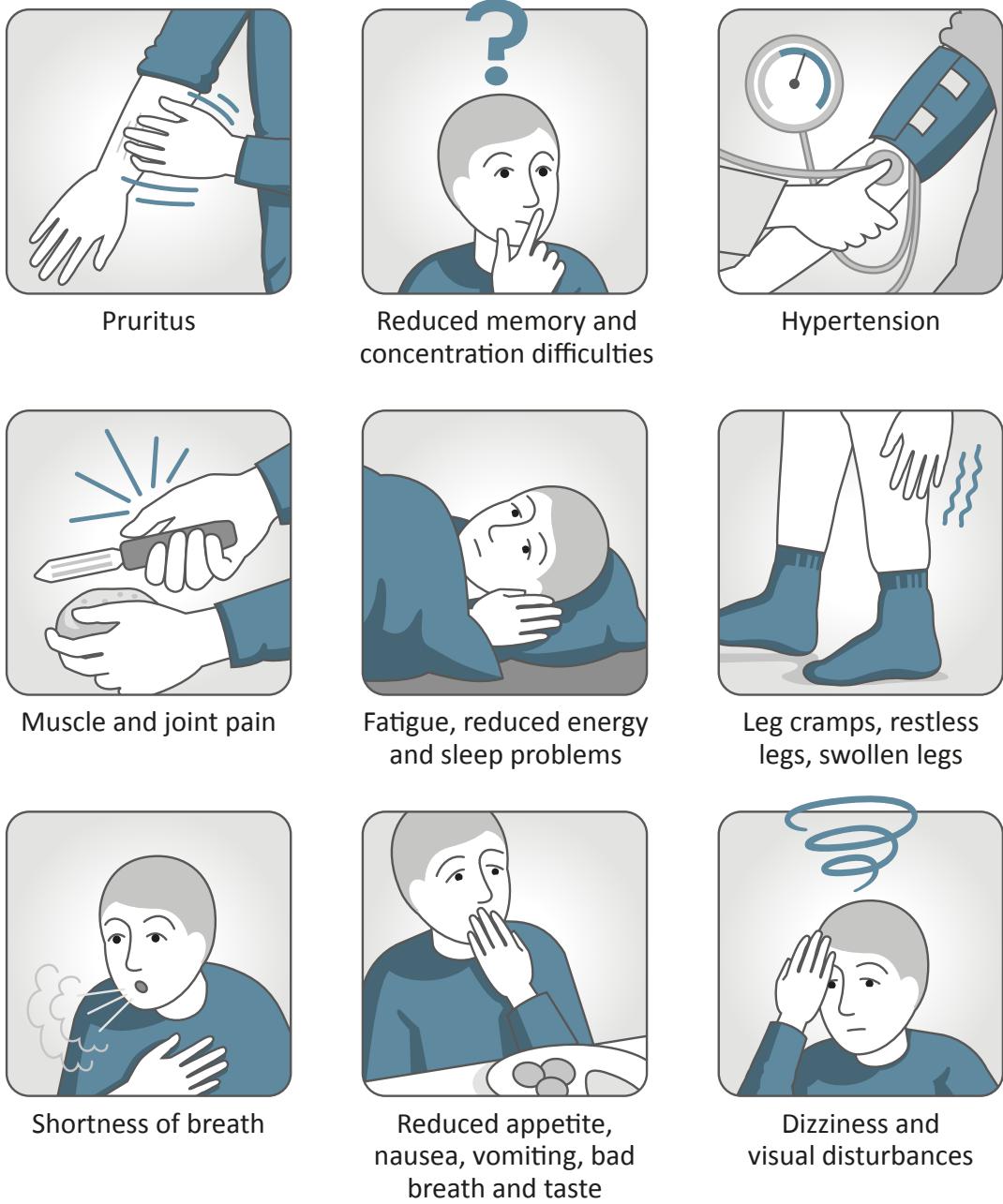
Together with you, the healthcare staff will work to delay the time when you need dialysis and slow down the progression of kidney failure.

We know it is important to start dialysis as planned. This means that you need to make a decision and to have a dialysis access established as soon as possible.

The symptoms of kidney failure are not necessarily symptoms that you would associate with kidney failure. The symptoms usually come quietly over a period of time, and you may not notice them because you have gotten used to them. But try to think back a year to remember how it was at that time.

Figure 2 shows the most common symptoms of kidney failure. Try to discuss these symptoms with a person who knows you very well. Maybe it is easier for that person to see these symptoms in you.

**Figure 2: Symptoms of kidney failure**



### **What is the choice?**

There are two options to replace a kidney with reduced function: a kidney transplant or dialysis. Many patients wish to have a kidney transplant. However, most patients have to choose a mode of dialysis because not all are suitable candidates for a kidney transplant and because there is a waiting list for kidney transplants.

There are two modes of dialysis:

**P-dialysis** where the peritoneal is used as a filter to cleanse your blood.

**Haemodialysis** where the blood is cleansed by a filter on a machine.

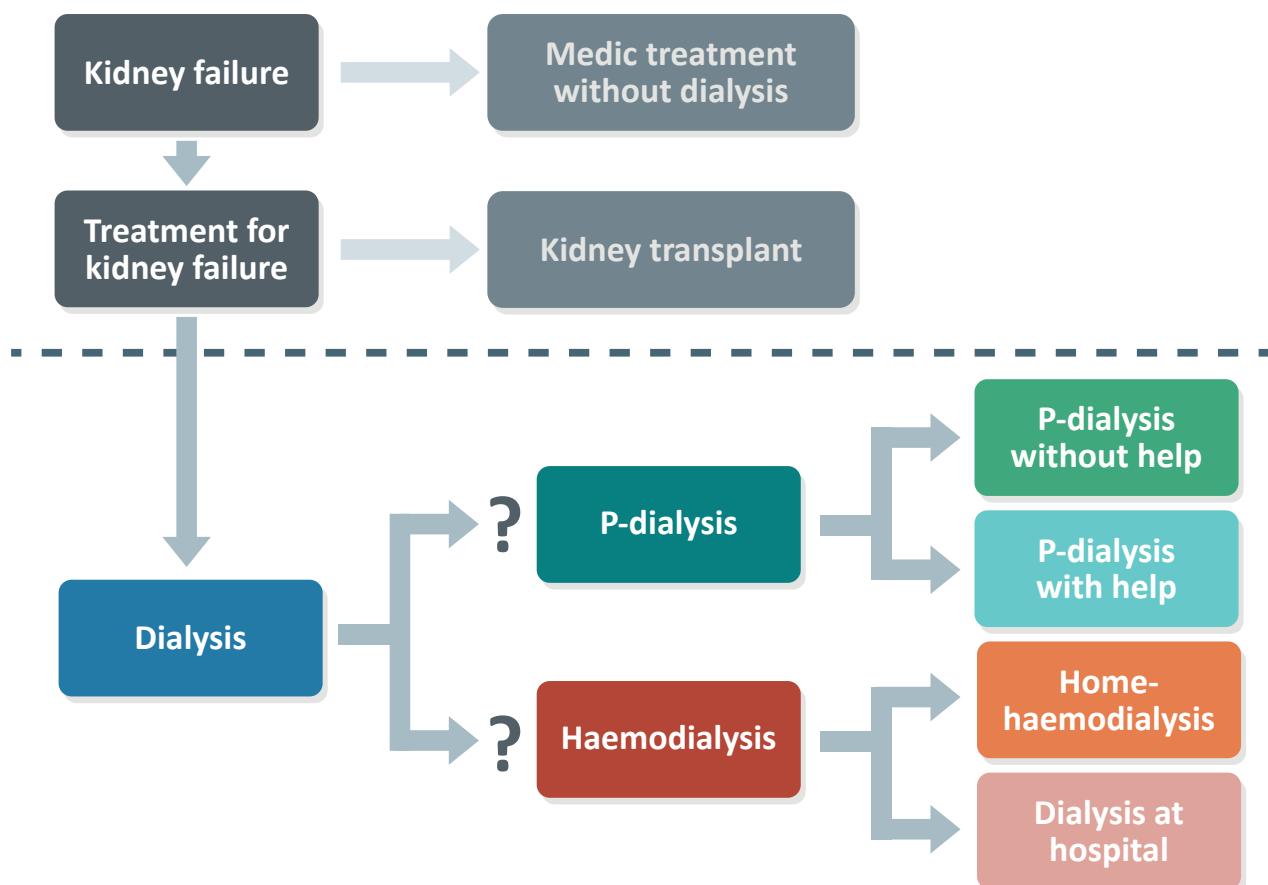
Both dialysis modes can be performed in your home.

Most patients can choose freely between the two dialysis modes, and both dialysis modes are equally good. However, it is recommended that you as a patient is involved in the decision-making concerning choice of dialysis mode.

You have to make many decisions when you have kidney failure. Figure 3 illustrates some of these decisions. The figure is divided by a dotted line. Decisions above the dotted line - marked with grey - are decisions that are prior to the decision you are about to make; the decision you have to make is shown below the dotted line.

You have to decide between P-dialysis and haemodialysis. If you are unable to manage the treatment yourself, you can in most cases get help. In most municipalities, you can get help at home for P-dialysis. In haemodialysis, you will undergo dialysis at the hospital where you will get the help needed.

Figure 3: Decision map



# Step two – about the options

The purpose of Step 2 is to provide insight into your options for dialysis as well as discuss the advantages and disadvantages of each dialysis mode.

## Which possibilities do I have?

Dialysis means cleansing and is a treatment where your body is cleansed for excess liquid and waste products.

There are two types of dialysis, P-dialysis and haemodialysis, and both can be performed with or without help:

- **P-dialysis without help**
- **P-dialysis with help**
- **Home haemodialysis**
- **Dialysis at hospital**

The four dialysis modes are briefly described below.

## P-dialysis without help

A sugary fluid is placed into the peritoneal during P-dialysis. The fluid extracts liquid and waste from the blood into the peritoneal. The dialysis fluid is led into the abdominal cavity through a thin plastic tube called a P-dialysis catheter. This catheter is operated into the stomach and is approximately  $\frac{1}{2}$  cm in diameter; about 30-50 cm is visible outside the stomach.

The fluids can be manually shifted in and out, for example, three or four times a day or by a machine at night when you sleep. A manual shift of fluids takes often about 30 minutes. In P-dialysis with a machine, the treatment takes 7-9 hours and 15 minutes for mounting and 15 minutes for dismounting of the machine.

It usually takes three to five days (of six hours) for you to be trained in P-dialysis treatment by specially trained nurses.

Equipment for the treatment will be delivered to your home. You must store equipment for either 7 or 14 days of treatment at a time. This corresponds to the size of a two wing wardrobe and the dialysis machine itself.

Every 6th to 8th week you meet for a follow-up at the hospital. It is possible to contact the hospital around the clock if problems arise related to your treatment.

The most frequent complication of P- dialysis is infection at the catheter exit site or in the peritoneal; infections are treated with antibiotics.



## P-dialysis with help

P-dialysis with help largely corresponds to P- dialysis without help. The treatment will often take place by a machine during your sleep at night. Instead of managing the treatment yourself, primary care staff will be trained to help you. The primary care staff will help you to the extent needed. For some, this means the staff will come to your home every morning and evening; for others, they will come to your home once during the day.



## Home haemodialysis

In haemodialysis, your blood is cleansed through a filter on a dialysis machine. The blood is led through a needle from your body to the filter on the dialysis machine and back into your body through another needle.

Most often a fistula is made in your arm where the two blood vessels, a vein and an artery, are sewn together. The needles used for dialysis leading the blood to the machine are placed in the arm with the fistula. If it is not possible to make a fistula, a haemodialysis catheter will be used, which is a plastic tube inserted into one of the large blood vessels in the chest through the skin.

In collaboration with the healthcare professionals, you plan when, how long and how often you will go through dialysis. We recommend that you have no less than 15 hours of dialysis each week divided into 4-6 dialysis sessions. The more dialysis you undergo, the more likely it is that you will experience fewer symptoms of kidney failure. Dialysis can take place both at daytime and during the night.

Usually, it takes three months (three to five days a week for four to six hours) to be trained for home haemodialysis. Specially trained nurses will teach you and the training takes place while you undergo dialysis.



Equipment for the treatment will be delivered to your home. You must store equipment for 14 days of treatment at a time, which corresponds to the size of a two wing wardrobe. In addition, you must store the dialysis machine and a water system (the size of a kitchen cabinet).

Every second or third month, you will meet for a follow-up at the hospital. It is possible to contact the hospital around the clock if problems arise related to your treatment.

The most frequent complications of home haemodialysis are:

- Difficulty placing the needles in the fistula
- Fistula or catheter infection. Infections are treated with antibiotics.

Some patients experience discomfort during dialysis and in the hours after; this is because the treatment is a strain on the body. This discomfort may appear as headache, fatigue, dizziness, cramps and a sudden drop in blood pressure. Frequency of dialysis and the duration of each dialysis may reduce these side effects.

## Dialysis at hospital

If you are not able or do not wish to manage haemodialysis yourself at home, you can get dialysis at the hospital.

This treatment is technically equivalent to home haemodialysis.

You are offered dialysis treatment three times a week for four hours. You will spend about five hours in the hospital three times a week, and you will also have to add time for transport back and forth to the hospital. Your scheduled dialysis appointments are organised according to your wishes to the widest extent possible. It will primarily be nurses who take care of your treatment, but it is expected that you participate in the treatment as much as possible.



If you are not able to transport yourself to and from the hospital, transportation will be arranged for you.

The most frequent complications of dialysis at the hospital are the same as in home haemodialysis. You may, however, more often experience headaches, tiredness, dizziness, cramps and a sudden drop in blood pressure due to the fewer dialysis sessions compared to home haemodialysis.

### **What are the advantages and disadvantages of each option?**

In Figure 4, you will find an overview of the most frequently asked questions by other patients who have had to decide on dialysis mode. The answers to the questions depend on which dialysis mode you choose. If you have any other questions, please ask the questions. You are also welcomed to ask additional questions to the answers given in the overview. Please note that P-dialysis with help does not have its own column, as it largely corresponds to P-dialysis without help. The answers specifically applying to P-dialysis with help are marked with a light green colour.

Figure 4: Overview of frequently asked questions

Dialysis choice	Peritoneal dialysis	Haemodialysis	
	P-dialysis without help	Home haemodialysis	Dialysis at hospital
	P-dialysis with help		
<b>How often will I need treatment?</b>	Every day. Either 7 – 9 hours at night and 15 minutes for mounting and dismounting, or 4 daily bag changes each lasting 30 minutes.	As often as you want. A minimum of 15 hours a week divided into 4-6 treatment sessions.	Three times a week. Every treatment session lasts 3 – 5 hours, and time for transport should be added.
<b>Do I need an operation?</b>	<b>Yes.</b> A P-dialysis catheter will be operated into your stomach.	<b>Yes.</b> If it is possible, you will have an operation in your arm, where two vessels are sewn together; this is called a fistula. If this is not possible, a dialysis catheter will be surgically placed in one of the big vessels in your chest.	<b>Yes.</b> If it is possible, you will have an operation in your arm, where two vessels are sewn together; this is called a fistula. If this is not possible, a dialysis catheter will be surgically placed in one of the big vessels in your chest.
<b>Who will take care of my treatment?</b>	You will. There will be meetings at the hospital if needed. If you have problems or questions you will be able to contact the hospital around the clock.	You will. There will be meetings at the hospital if needed. If you have problems or questions you will be able to contact the hospital around the clock.	A nurse will take care of your treatment at the hospital in collaboration with you. We expect you to participate in the treatment as much as possible.
	If you are not able to take care of the treatment yourself, in most municipality you are able to get help at your home.		
<b>Do I need to storage equipment at home?</b>	<b>Yes.</b> The dialysis machine and material for the dialysis (size of a two wing wardrobe closet).	<b>Yes.</b> The dialysis machine, a water system (size of a kitchen cabinet) and some materials for the dialysis (size of a two wing wardrobe closet).	<b>No.</b>
<b>Which complications may arise in relation to my treatment?</b>	Infection and other problems with the fistula or the P-dialysis catheter.	Infection and other problems with the fistula or the dialysis catheter.	Infection and other problems with the fistula or the dialysis catheter, as well as headache, tired-ness, muscle cramps and lowered blood pressure.
<b>How does the treatment influence my residual kidney function?</b>	Your residual kidney function will diminish.	Your residual kidney function will diminish – probably faster than if you are on P-dialysis.	Your residual kidney function will diminish – probably faster than if you are on P-dialysis.
<b>For how long will the treatment be effective?</b>	This is a time-limited treatment.	This is a permanent treatment to go on as long as you or a relative is able to take care of it.	This is a permanent treatment.

Dialysis choice	P-dialysis	Haemodialysis	
	P-dialysis	Home haemodialysis	Dialysis at hospital
	P-dialysis with help		
<b>What am I allowed to eat and drink?</b>	There will be a few things you should not eat and drink. Maybe you will need to be careful concerning the amount of fluids you drink.	There will be a few things you must not eat and drink. The more dialysis sessions you choose, the more freely you can choose to eat and drink the few things you should not eat and drink.	There will be several things you should not eat and drink. The amount of fluids you are allowed to drink will often be restricted.
<b>How will it influence my medicine consumption?</b>	Some will need extra medicine due to reduced kidney function.	If you do dialysis every day, many can avoid or reduce medicine intake	Most people need extra medicine due to reduced kidney function.
<b>How will it influence my life?</b>	You will be able to continue working and do what you usually do.	You can customize the time and duration of your dialysis according to your work and leisure activities.	You will have regular appointments for dialysis and need to adjust your life accordingly.
<b>What does it mean for my physical activities?</b>	When swimming in the ocean or lakes you have to put on a special dressing on your P-dialysis catheter. There are different recommendations for using a swimming pool. You should avoid heavy lifting.	If you have a fistula, you can use swimming pools and swim in the ocean and lakes. You should avoid blows to the fistula. If you have a dialysis catheter you cannot use a swimming pool.	If you have a fistula you can use swimming pools and swim in the ocean and lakes. You should avoid blows to the fistula. If you have a dialysis catheter you cannot use a swimming pool.
<b>Can I still travel?</b>	Yes. It is possible to have liquids delivered to your holiday destination. Planning is needed when travelling abroad.	Yes. It is possible to borrow a travel dialysis machine at several centres. You can also book a dialysis session at a dialysis centre at the destination you are travelling to. Planning is needed.	Yes. You can book a dialysis session at a dialysis centre in the country/at the destination you are travelling to.
	Planning is needed. It requires that you have someone to help you at the destination of your holiday.		
<b>Will I experience changes in my appearance?</b>	The P-dialysis catheter is placed in your stomach. You may experience that your stomach is a little larger than usual because of fluid in the abdominal cavity. You may experience a slight weight increase.	The fistula is placed in one arm. The fistula will develop, and blood vessels will be more pronounced and maybe there will be a pouch on the vessel. You may feel a constant buzzing in the fistula. The dialysis catheter is placed in the chest.	The fistula is placed in one arm. The fistula will develop, and blood vessels will be more pronounced and maybe there will be a pouch on the vessel. You may feel a constant buzzing in the fistula. The dialysis catheter is placed in the chest.
<b>What does these changes mean to my sex life?</b>	No direct changes.	No direct changes.	No direct changes.

# Step three – about the decision

The purpose of the third meeting is that you and your relatives together with a nurse will make a decision about your future mode of dialysis.

We encourage you to prepare for the meeting with your relatives using the decision support template on the next two pages (Figure 5).

Figure 5: Decision guide, for you who have to make decision regarding dialysis choice

## 1. Clarify your decision

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with  
making a choice?

Not thought about it  
 Thinking about it

Close to choosing  
 Made a choice

## 2. Explore your decision

### Knowledge

List the options and benefits  
and risks you know.

### Values

Rate each benefit and risk using  
stars (\*) to show how much  
each one matters to you.

### Certainty

Choose the option with the benefits  
that matter most to you. Avoid the  
options with the risks that matter  
most to you.

	Reasons to Choose this Option (Benefits/Advantages/Pros)	How much it matters to you: 0* not at all 5* a great deal	Reasons to Avoid this Option (Risks/Disadvantages/Cons)	How much it matters to you: 0* not at all 5* a great deal
P-dialysis without help				
P-dialysis with help				
Home haemodialysis				
Dialysis at hospital				

### Which option do you prefer?

<input type="checkbox"/> P-dialysis without help	<input type="checkbox"/> P-dialysis with help	<input type="checkbox"/> Home-haemodialysis	<input type="checkbox"/> Dialysis at hospital	<input type="checkbox"/> Unsure
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### Who supports your decision?

Who else is involved?	Who:	Who:	Who:	
Which option do they prefer?				
Is this person pressuring you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No
How can they support you?				
What role do you prefer in making the choice?	<input type="checkbox"/> Share the decision with... <input type="checkbox"/> Decide myself after hearing views of...		<input type="checkbox"/> Someone else decides...	

### 3. Identify your decision making needs

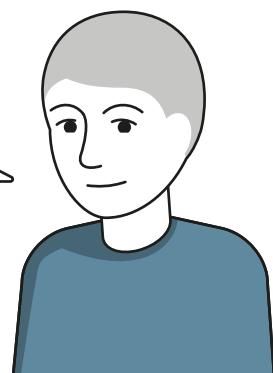
<b>Knowledge</b>	Do you know the benefits and risks of each options?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>Values</b>	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>Support</b>	Do you have enough support and advice to make a choice?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>Certainty</b>	Do you feel sure about the best choice for you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

The decision concerning choice of mode of dialysis is important for your life, both in terms of physical, mental and social conditions. Please note that your decision regarding dialysis choice can be changed. The decision can be changed before you start dialysis, but also when you have started dialysis. If your dialysis choice does not match your expectations, talk to your contact nurse or contact doctor.

Perhaps you have to start dialysis in a month, maybe in a year. If dialysis is delayed, reconsider the decision at least every six months, to see if the decision you made still fits you and your life and discuss it with your relatives, your contact doctor and contact nurse. When the time comes for actually starting dialysis, believe in the choice you have made and spent a lot of energy making.

"It is and will be a mess. I would prefer to be free of dialysis. But when it can not be different, I would like some options, so I can find the dialysis mode I prefer. I have gained so much knowledge about this, so I'm ready. It's entirely my own decision and I'm convinced that's the right one."

Bjarne Brøchner, a patient



# Glossary

Dialysis:	Artificial cleansing of the blood for waste products and excess liquid. Dialysis replaces the lost kidney function.
Haemodialysis:	Cleanses the blood and removes excess liquid through a filter.
P-dialysis:	Cleanses the blood and removes excess liquid through the peritoneal.
Kidney transplant:	May either occur with a kidney from the deceased donor or a kidney from a living donor. Requires lifelong treatment to avoid that the body rejects the transplanted kidney.
Fistula: the	A fistula is made surgically by sewing together an artery and a vein in the arm so it can be used for cannulation.
Haemodialysis catheter:	Plastic tube surgically inserted into one of the big blood vessels through a small hole in the skin in the chest or the neck.
P-dialysis catheter:	Soft silicone tube surgically placed in the abdominal cavity.
Dialysis access:	An overall term for accesses which can be used for dialysis, i.e. a fistula, a haemodialysis catheter and a P-dialysis catheter.

## Further information regarding dialysis choice

- The homepage of the National Kidney Association: <http://nyre.dk>
- The APP from the National Kidney Association: <http://dialysetest.dk.linux69.unoeuro-server.com/www/>
- Sundhed.dk: [https://www.sundhed.dk/borger/patienthaandbogen/nyrer-og\\_urinveje/sygdomme/diverse/dialyse/](https://www.sundhed.dk/borger/patienthaandbogen/nyrer-og_urinveje/sygdomme/diverse/dialyse/)

This decision aid has been developed by patients and healthcare professionals in collaboration. For further information about development and evaluation, please contact clinical nurse specialist and PhD, Jeanette Finderup [jeajee@rm.dk](mailto:jeajee@rm.dk). The development and evaluation of this decision aid has not received any industrial funding. Last updated the 29<sup>nd</sup> of June 2020.