

Patient Decision Aid

Kidney Failure Treatment Options

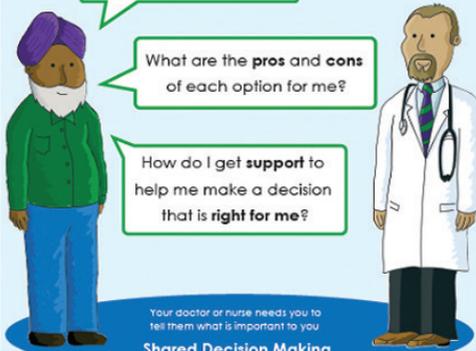
Sussex Kidney Unit

Ask 3 Questions

Normally there will be choices to make about your healthcare. Make sure you get answers to these three questions:



- What are my **options**?
- What are the **pros** and **cons** of each option for me?
- How do I get **support** to help me make a decision that is **right** for me?



Your doctor or nurse needs you to tell them what is important to you.

Shared Decision Making

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This booklet will help you make an informed decision regarding treatment options available to you when you have chronic kidney disease (CKD) and are nearing established kidney failure. There is no cure for chronic kidney disease, but there are treatment options available. The 'decision aid' is aimed at helping you make the right treatment decisions.

When your kidneys are working less than 20% (GFR <20%) you will be invited to attend a small group patient education session or one to one session. This will involve a discussion on the various types of treatment options, known as renal replacement therapy (RRT). You will be expected to make decisions at different stages during the progression of the kidney disease.

Do I want Renal Replacement Therapy?

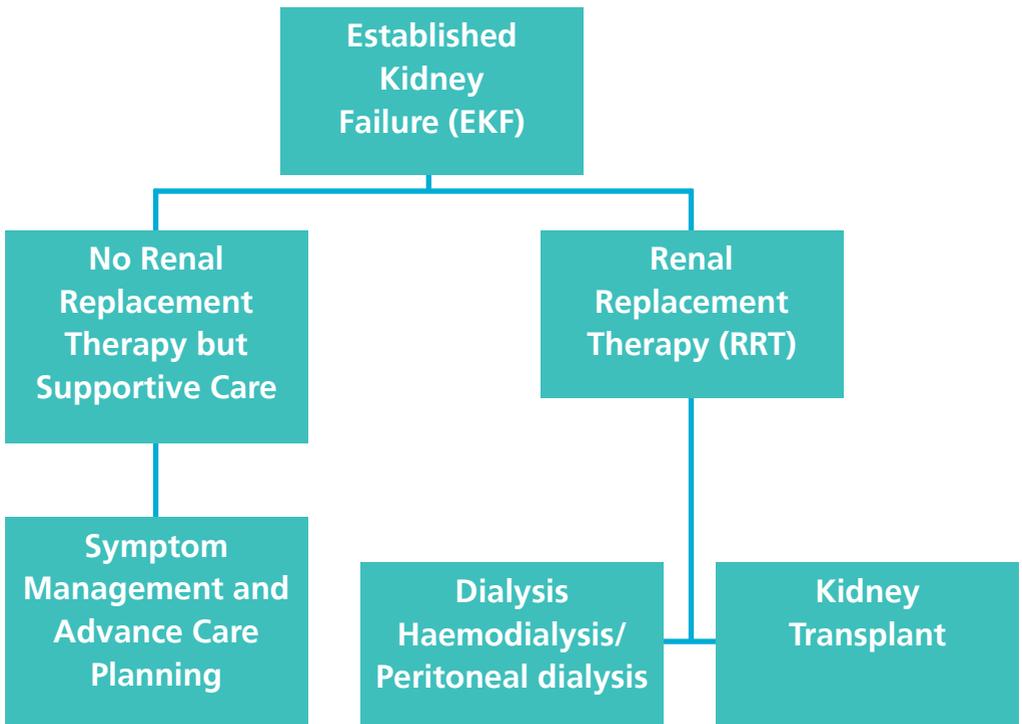
You will need to decide whether to have a renal replacement therapy. Renal replacement therapy means a treatment that will act as a substitute for the kidney in removing waste products from your blood.

Established kidney failure can be treated using 3 main types of treatment:

- A** Receiving a kidney transplant
- B** Dialysis (Peritoneal dialysis or haemodialysis)
- C** Supportive Care (which means treating you with medication and not dialysis or transplant).

Established Kidney Failure (EKF)

People with chronic kidney disease may progress to develop Established Kidney Failure (EKF) also known as renal failure. This means that their kidneys are working less than 15% and the kidneys will be less able to perform the functions such as removing waste substances produced from the body. The management of your kidney disease will change. You will be expected to make a decision with the help of your kidney doctor or nurse about the type of renal replacement therapy you would prefer; either dialysis or kidney transplant. If you choose not to have any renal replacement therapy you will be offered supportive care also known as maximum conservative care. Please see diagram below.



Why do I need to make a decision?

When you are told your kidneys are failing, it is difficult to predict how long it will take before they fail completely. You need to make a decision about which type of treatment you would prefer before your kidneys start working at less than 15% for the following reasons.

You will need to:

- Decide which dialysis treatment best suits your life-style.
- Allow the kidney unit to plan and manage your kidney disease.
- Have a small operation to create an 'access point' in your body to enable dialysis to take place.

Please be aware that:

- It can take up to several weeks to create a fully functioning access point if you choose haemodialysis.
- Renal replacement therapy requires preparation time depending on the type of treatment.

Not all renal replacement therapies are suitable for everyone. You need to discuss with your kidney care team which therapies are suitable for you.

If you decide you want to be assessed for a kidney transplant you will need various tests. It is needed to determine your fitness and suitability for the transplant operation.

Renal replacement therapies

If you choose to have a replacement therapy, we will help you choose the treatment and prepare you for your chosen type of replacement therapy.

Receiving a transplant

Kidney transplant is a type of renal replacement therapy but is not suitable for all patients.

What is a kidney transplant?

A kidney is removed from a donor (human) and placed inside a recipient (the person who has established kidney failure). This is a surgical procedure performed under general anaesthetic.

Where does the kidney come from?

The kidney comes from two main sources.

Cadaveric (deceased) Donors

These kidneys come from someone who has died suddenly but was previously healthy. These people may have registered to be organ donors or their next of kin will have agreed to organ donation.

Living Donors

These are people who donate one of their kidneys to another person. There are different types of living donors, live related and live unrelated donors.

Live related donors

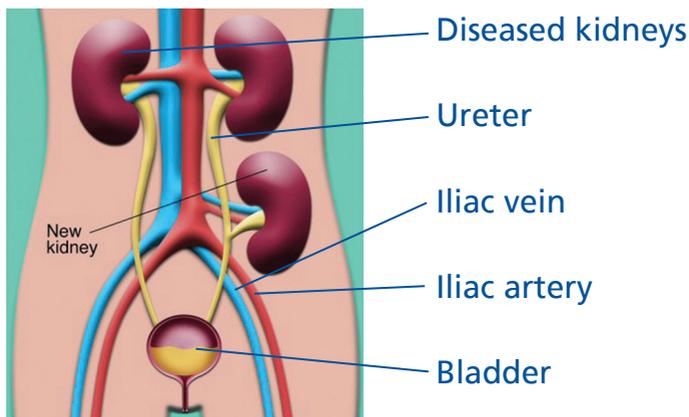
These are living donors who donate one kidney to a blood relative who has established kidney failure.

Live unrelated donors

These are living donors who donate one kidney to a recipient who is not related by blood for example a friend, spouse, partner or work colleague.

Where is the kidney placed?

The kidney is transplanted either to the left or right side of the lower abdomen near to your bladder and is connected to the blood vessels supplying the leg as shown below.



Only one kidney is transplanted as it can do the work of the two kidneys. Your own kidneys are not usually removed even though they are not working.

It is possible to have a kidney transplant before you need to start dialysis also known as **pre-emptive kidney transplantation**. If you choose to have a pre-emptive kidney transplant you will need to look for a **potential live donor**. The person (potential live donor) who decides to give you one of their kidneys will have to contact the pre-transplant sister about their decision to donate.

What is involved?

Which ever type of kidney transplant you choose to have whether it is a live donor or cadaveric kidney transplant, you will have to be prepared to:

- 1 Undergo a series of investigations to ensure that you are suitable to undergo this operation.
- 2 Undergo an operation at short notice.

- 3 Take tablets regularly for as long as the transplant is working to prevent your body from rejecting the transplanted kidney.
- 4 Attend regular follow-up clinics.

What are the advantages and disadvantages of a kidney transplant?

Advantages	Disadvantages
You will not need to dialyse so you will have a better quality of life.	You may experience change in your body image.
Continue working with minimum restrictions	You will need to tell your employer that you may need to be away from work without notice for the transplant surgery.
Able to travel and have holidays	You should be available at short notice
No fluid restrictions	There are risks involved in having any operation
Minimum dietary restrictions	Your body may try to reject the kidney
Improved feeling of wellbeing	You will have a higher risk of infection due to the drugs and you may experience other side-effects
Improved sexual function and ability to have children	You will have to take tablets every day

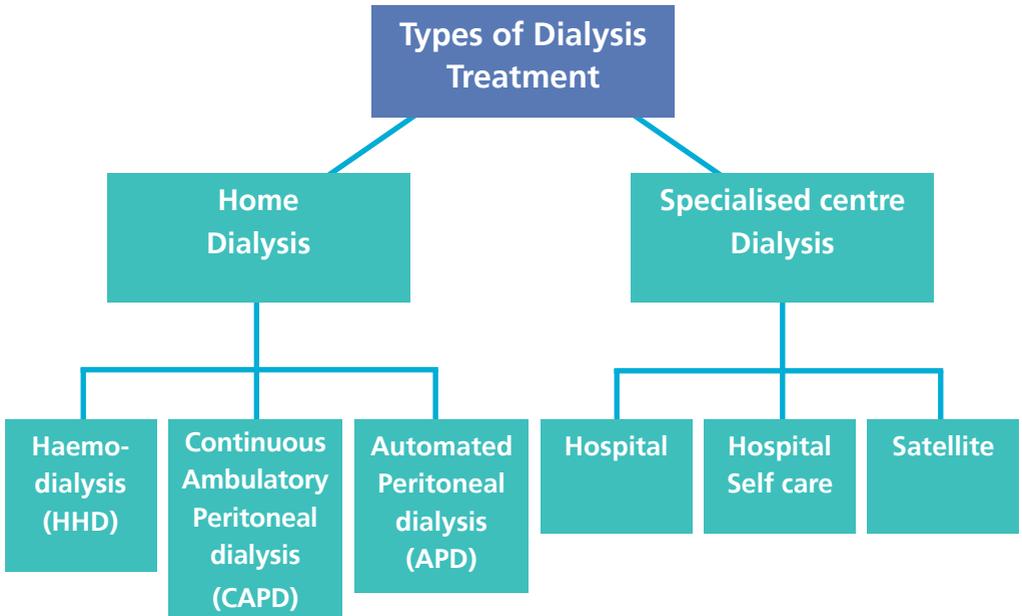
Please discuss your decision to have a kidney transplant with your kidney doctor or nurse.

Types of dialysis treatment

People who choose dialysis have to make a decision between the different types of dialysis treatment. All dialysis treatments allow waste products to be removed from the body using medical equipment. For most people the dialysis options work equally well however each option has possible side effects, can cause long term health problems and will impact on your life.

Choosing a treatment option

You first need to decide whether you want dialysis treatment at home, satellite unit or in the hospital as shown below.



You can dialyse at a satellite unit near where you live, at home or come to the hospital.

Peritoneal dialysis (PD)

If you choose peritoneal dialysis you will have a small operation for a tube (a peritoneal dialysis catheter) to be put in your peritoneal cavity in your abdomen. The peritoneum is a continuous membrane which lines your abdomen. The catheter allows fluid (dialysate fluid) to be drained in and out of your peritoneum to enable dialysis to take place. You can do *continuous ambulatory peritoneal dialysis (CAPD)* four times a day or overnight *automated peritoneal dialysis (APD)*.

Haemodialysis (HD)

If you choose haemodialysis you will have a small operation to create an 'access point' in your body to enable dialysis to take place. Home haemodialysis (HHD) and peritoneal dialysis are also known as *home therapies*.

Comparing the different types of dialysis treatment

Pages 11-16 compares the different types of dialysis treatment. This will help you understand what is involved in each type of dialysis treatment option; enable you to make an informed decision and the right choice of treatment.

Hospital treatment

The picture below shows a patient dialysing in the hospital.



Hospital Treatment		
	Self care haemodialysis	Hospital haemodialysis at a specialist centre
Where will dialysis take place (Location)	At the hospital or satellite unit.	At the hospital or satellite unit.
Usual number of sessions	3 times in a week: Monday, Wednesday and Friday or Tuesday, Thursday and Saturday.	3 times in a week: Monday, Wednesday and Friday or Tuesday, Thursday and Saturday.
Usual length of a session	4 hours per session plus waiting and travelling time.	4 hours per session plus waiting and travelling time.
Usual time dialysis sessions happen	Sessions start early morning, lunch time and twilight. Dialysis slots are allocated to you depending on the availability and your personal circumstances.	Sessions start early morning, lunch time and twilight. Dialysis slots are allocated to you depending on the availability and your personal circumstances.
What can I do during dialysis	Most people sit on a chair or lie on a bed during dialysis session. People tend to read, listen to music, watch TV or sleep during the sessions.	Most people sit on a chair or lie on a bed during dialysis session. People tend to read, listen to music, watch TV or sleep during the sessions.
How dialysis works	Automatically by a dialysis machine. Blood is taken from your access point (fistula or a line), cleaned by the machine and returned into your body.	Automatically by a dialysis machine. Blood is taken from your access point (fistula or a line), cleaned by the machine and returned into your body.
Who carries out the dialysis	Patients are trained to self-manage aspects of the dialysis session.	Staff at the hospital or satellite dialysis centre carry out the dialysis.
Equipment needed	A dialysis machine, reclining chair or a bed.	A dialysis machine, reclining chair or a bed.
Travel to treatment	Hospital transport is provided, but you may wish to make your own transport arrangements.	Hospital transport is provided, but you may wish to make your own transport arrangements.

Home treatments

The picture below shows a haemodialysis set up at home. It also shows you the water unit.

Haemodialysis machine

Set of drawers
containing disposables
dialysis lines and fluid



Plumbing set up

Water treatment unit

Reclining chair



Patient dialysing at home

Fistula (access point)

Dialysis tube

Dialysate fluid



When the patient is not dialysing, He draws the curtain across to cover the dialysis machine and water unit as shown in the picture below.

Curtain pulled to cover dialysis and water unit



Peritoneal dialysis

The picture below shows a patient doing a continuous ambulatory peritoneal dialysis exchange (CAPD) at home. He does the exchange four times a day.

Peritoneal dialysis catheter



Dialysate fluid draining in

Used dialysate fluid drained out

This is a picture of an overnight automated peritoneal dialysis (APD) machine.

Dialysate

Automated peritoneal dialysis machine

Connecting tubes



This picture shows an overnight automated PD machine set up ready for a patient to connect at home.

Automated peritoneal dialysis machine

Dialysate fluid



The picture shows a patient who is connected to the automated PD machine dialysing over the night at home.

Automated peritoneal dialysis machine connected to patient



HOME TREATMENTS

	HHD Haemodialysis at home	CAPD Continuous Ambulatory Peritoneal Dialysis	APD Automated Peritoneal Dialysis
Where will dialysis take place (Location)	At home.	Most people choose home or work but it can be done in any clean place.	It is done at home in your bedroom.
Usual number of sessions per a week	At least 3-6 days per week.	4 times every day.	Every night.
Usual length of session	About 2 to 4 hours per session.	About 30 minutes per session.	About 8 hours per session.
Usual time dialysis sessions happen	People usually choose day time or evening.	People usually choose day time.	People usually choose night time.
What can I do while I am dialysing	Most people sit on a couch or lie on a bed during dialysis. People tend to read, listen to music, watch TV or sleep during the sessions.	You can be sitting or lying down. You can also do it during meal times. People tend to read, listen to music or watch TV.	Most people are asleep.
How dialysis works	Automatically by a dialysis machine	Manually by yourself. The used fluid is drained out and a fresh supply drained in by gravity.	Automatically by the APD machine. The machine pumps fluid in and out of your tummy while asleep.

Who carries out the dialysis	You will be trained to carry out HHD yourself. In most cases a carer is trained to help you carry out HHD. A carer may be a family member or friend.	You will be trained to carry out CAPD.	You will be trained to carry out APD. In some cases a carer is trained to help carry out the APD. A carer may be a family member or friend.
Equipment needed	The dialysis kits are delivered by the kidney service 1) A dialysis machine 2) A reclining chair 3) A water treatment unit 4) Dialysate fluids 5) Disposable tubes to set up the machine 6) The machine requires electricity supply and plumbing	The dialysis kits are delivered by the kidney service The kits contain 1) Bags filled with clean dialysate fluid and empty bags to drain out the used dialysate fluid	The dialysis kits are delivered by the kidney service. It includes 1) An APD machine 2) Bags filled with clean dialysate fluid and empty bags to drain out the used dialysate fluid 3) The machine requires electricity supply 4)The machine is usually the size of a small suitcase
Where to store equipment	1) The supplies can be stored anywhere that is convenient at home; in a cupboard, clean space in a basement, in a garage or a shed 2) The stores are delivered monthly	1) The supplies can be stored anywhere that is convenient at home; in a cupboard, a clean space in a shed or in a garage 2) The stores are delivered monthly	1) The supplies can be stored usually in a cupboard, a clean space in a shed, or garage 2) The machine and supplies can be stored anywhere at home preferably where you sleep at night 3)The stores are delivered monthly
Travel to treatment	Stay at home	Stay at home	Stay at home

Choosing not to have any renal replacement therapy

If you choose not to have any replacement therapy, you will be cared for on the supportive care pathway also known as maximum conservative care. Supportive care is treating you without dialysis or transplant. Supportive care aims to maintain your kidney function as far as it is possible and treat the symptoms with medication and diet. People who choose supportive care may die of another illness or as a result of their kidney disease. Supportive care will also enable you to plan for your future care. This is also known as '**Advance Care Planning (ACP)**'.

What is Advance Care Planning?

This is a voluntary process of discussion between you and those who provide care for you which involves:

- Having an open conversation to explore your options
- Declining specific treatment if you wish
- Appointing someone to make decisions on your behalf when you are not capable (that is using a lasting power of attorney)
- Identifying your wishes and preferences and having it documented
- Letting people know your wishes

If you want more information on Advance Care Plan speak to your kidney doctor or ask one of the nursing staff when you attend clinic or phone renal outpatients on the number provided on page 25.

Helping you to think about your treatment options

The following questions will help you and your carers think about your treatment options and help you make the right choice. There are three different sets of questions in section A, B, and C.

Questions in section A and B ask you to reflect on what is important to you in the way you live your life and how dialysis will fit into your life style. Section C asks you to rate how well you think the dialysis options would fit into your life style. Please consider how you can continue with your daily activities and which of the dialysis options will enable you to achieve it.

Each of the answers you tick has a numerical value. At the end of each section please add up the scores and use the score table to find out the meaning. This will enable you identify which activities are very important to you and how each dialysis treatment will allow you to perform those activities.

Please complete the questions in section A, B and C by ticking the boxes that best describe your activities and the treatment option that will best suits your lifestyle mentioned in pages 6-17.

A) Please indicate with a tick how important each of the following activities are to you.

Activities	Not important 1	Important 2	Very important 3
Looking after others e.g. caring for children, for family members, for pets			
Study e.g. degrees, evening classes or part time education			

Socialising e.g. spending time with friends and/or family			
Household e.g. cooking, washing up, running errands, doing laundry, house cleaning			
Religious practices			
Sleeping i.e. maintaining quality and quantity of sleep			
Relaxing, resting, meditating, watching TV, using internet, using phone			
Local travel e.g. going on public transport or driving			
Hobbies e.g. gardening, fishing, crafting, playing music, knitting			
Holidays and breaks away from home			
Work (job paid/unpaid)			
Leisure e.g. walking, cycling, yoga, dancing, swimming and other sporting activities			
Total Score			

TOTAL SCORES	MEANING OF SCORES
1-12	I will not be concerned if my treatment choice limits my ability to perform the activities listed above.
13-26	I will be slightly concerned if my treatment choice limits my ability to perform the activities listed above.
27-36	My treatment choice should enable me perform my important activities listed above.

In section **B** you need to think about how each type of treatment option may **fit into your lifestyle**.

B) To what extent will each of the following allow you to do those activities that are important to you in page 18-19? Please tick

Type of treatment	Not at all 1	Moderate 2	Completely 3
Hospital haemodialysis			
Hospital self care haemodialysis			
Home haemodialysis (HHD)			
Continuous ambulatory peritoneal dialysis			
Automated peritoneal dialysis (APD)			
Kidney transplant			
Supportive care			

SCORES	MEANING OF SCORES
1 (not at all)	This treatment choice will not allow me to perform the activities important to me.
2 (moderate)	This treatment choice will allow me to perform some of the activities important to me.
3 (completely)	This treatment choice will enable me perform most or all the activities that are important to me.

In section **C**, you have to think about what is important to you and if there is something you might consider compromising to enable you fit your chosen treatment option into your life.

C) At this point in your life, which of the following treatments will enable you to perform your very important activities? Please tick

Type of treatment	Not good 1	Moderately good 2	Very good 3
Hospital			
Hospital self care haemodialysis			
Home haemodialysis (HHD)			
Continuous ambulatory peritoneal dialysis			
Automated peritoneal dialysis (APD)			
Kidney Transplant			
Supportive care			

TOTAL SCORES	MEANING OF SCORES
1 (not at all)	This type of treatment will not allow me to perform the activities important to me.
2 (moderate)	This type of treatment will allow me to perform some of the activities important to me.
3 (completely)	This type of treatment will allow me to perform the most or all of the activities important to me.

Time to make your decision

Having read the information provided and carefully thought about the different treatment options, which one do you think will allow you to do the activities that are important to you listed in page 18-19. Choose the option that will enable you perform the activities important to you. Please indicate with a tick.

Type of treatment	Definitely yes	Unsure	Definitely no
Hospital haemodialysis			
Hospital self care haemodialysis			
Home haemodialysis (HHD)			
Continuous ambulatory peritoneal dialysis (CAPD)			
Automated peritoneal dialysis (APD)			
Kidney transplant			
Supportive care			

Now that you've read all the information in this booklet please carefully ask your self these 3 questions:

- 1. What treatment option is best for me?**
- 2. What are the pros and cons of each option for me?**
- 3. How can I get support to help me make a decision that is right for me?**

Please communicate your chosen treatment which will allow you to perform the activities you deem very important to you, to your kidney doctor or nurse.

Glossary

Term	Meaning of term
Chronic Kidney Disease (CKD)	It is a long term condition used when the kidneys do not work properly
Established renal failure (ERF)	It is stage in CKD when the kidney is working below 15%
Haemodialysis (HD)	A treatment that works like the kidney to remove toxins and excess water from the body.
Peritoneal Dialysis (PD)	A treatment that removes waste products and excess water from the body allowing you to put fluid in and out of your tummy using a tube.
Transplant	A surgical operation performed to put a kidney donated from another person in a recipient.
Fistula	It is a form of access created to enable haemodialysis to take place. A small operation is done to join a vein and an artery together under the skin, usually in the forearm.
Renal replacement therapy (RRT)	A form of treatment that does some of the work of the kidneys when it is working less 15%
Supportive care	A form of treatment without dialysis
Continuous ambulatory peritoneal dialysis	A type of dialysis treatment that is usually carried out 4 times each day
Automated peritoneal dialysis (APD)	A type of dialysis treatment that is usually carried out during the night using a machine
Donor	A person who donates one of their kidneys to another person with chronic kidney disease
Recipient	A person who receives the donated kidney

Contacts

If you need more information please call the following:

Renal outpatients department:

01273 664559

Patient education and choice options

Pre-dialysis nurse:

01273 696955 Extension 7616

Advanced kidney disease lead nurse:

01273 696955 Extension 7579

Pre-transplant nurse:

01273 696955 Extension 7478

Renal care planning nurses:

01273 664559

Home therapies:

01273 696955 Extension 7573 or 7584

Self care dialysis:

01273 692005

Main dialysis unit:

01273 696955, Extension 4605

You can also contact them on the following address:

Brighton and Sussex University Hospitals NHS Trust

Royal Sussex County Hospital

Sussex Kidney Unit

Renal Outpatients Department

Eastern Road, BN2 5BE

Worthing Satellite 01903 285244

Crawley Satellite 01293 601920

Bexhill Satellite 01424 731824

Useful information and video resources

South Eastern Kidney Patients Association (SEKPA): www.sekpa.org

British Kidney Patients association: www.britishkidney-pa.co.uk

Renal Patients Association: www.patients-association.com

UK National Kidney Federation: www.kidney.org.uk

Kidney Care Matters: www.kidneycare.nhs.uk

Renal patient view: www.renalpatientview.org

Edinburgh Renal Unit: ww.edren.org

Kidney Dialysis Information Centre: www.kidneydialysis.org.uk

Kidney Patient Guide: www.kidneypatientguide.org.uk

Kidney Research UK: www.kidneyresearchuk.org

Shared Decision Making (SDM) – NHS:

<http://sdm.rightcare.nhs.uk/pda/>

Buckfield Dialysis: <http://www.youtube.com/user/BuckfieldDialysis>

NHS Kidney care resources: <http://www.kidneycare.nhs.uk/resources/>

NHS Chronic Kidney Disease:

www.nhs.uk/conditions/Kidney-disease-chronic/

NHS Dialysis: www.nhs.uk/conditions/dialysis/

NHS Kidney care: www.kidneycare.nhs.uk/

NICE Guidelines: <http://guidance.nice.org.uk/>

The Renal Association: www.renal.org

UK Renal Registry: www.renalreg.com/

Bekker HL, Mooney A, Wilkie M, Winterbottom A, Gavaruzzi T, Summers B, Stiggelbout A, Tupling K, Crane D, Latchford G, Mathers N, Davies S. The Yorkshire Dialysis Decision Aid. (2012). University of Leeds: UK

If you do not understand this leaflet, we can arrange for an interpreter.

إذا كنت لا تستطيع فهم محتويات هذه النشرة فيمكننا عمل الترتيبات لتوفير مترجم شفوي لك.

এই প্রচারপুস্তিকাটি যদি আপনি বুঝতে না পারেন, তবে আপনার জন্য আমরা একজন অনুবাদকের ব্যবস্থা করে দিতে পারি

如你唔明白本單張的內容，我們可安排口譯員服務。

如你唔明白本傳單的內容，我們可安排口譯員服務。

اگر مندرجات این جزوه را نمیفهمید، ما می‌توانیم مترجم در اختیارتان بگذاریم.

Jeśli masz trudności w zrozumieniu tej ulotki, możemy zorganizować tłumacza.

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Disclaimer
The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

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