Treatment Options for People with Advancing Chronic Kidney Disease (CKD)

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To see all of our current patient information leaflets please visit www.uhb.nhs.uk/patient-information-leaflets.htm
Introduction

It is important for people with chronic kidney disease to be actively involved and supported in making decisions about their care and in choosing the treatment option that is right for them. Your kidney doctor and nurse will explain your kidney function level and discuss your current and future care plan to keep you as healthy as possible.

As your kidney function drops to about 20 (eGFR of 20 ml/min/1.73m²) the doctors and nurses will start to talk to you in more detail about the different treatment options for kidney failure. Support will be given to help you to think about and choose the best treatment for you.

This leaflet explains some of the symptoms you may experience as your kidney function falls and gives a simple guide to the full range of treatment options that are available. These include:

- Kidney transplantation
- Home therapies (dialysis at home) and self care
- Unit based haemodialysis
- Conservative kidney management

There are separate leaflets on each of the treatment options which give you more in depth information (see other sources of information at the end of the leaflet).
Symptoms

In the early stages of CKD you often have no symptoms. As your kidney function falls you may begin to experience some of the following:

- Tiredness
- Itching
- Feeling sick (nauseated) or vomiting (being sick)
- Reduced appetite – you may also have a strange metallic taste in your mouth
- Loss of weight
- Puffy ankles
- Shortness of breath, especially when lying down
- Problems sleeping
- Not passing as much urine
- Difficulty in concentrating and remembering things
- Cramps in your legs

If you are experiencing the worsening of any of these symptoms, please let your kidney doctor or nurse know as your medication or care plan may need to be altered.
Kidney transplantation

A kidney transplant involves an operation where a healthy kidney from one person (called a donor) is placed into the body of a person (called a recipient) with chronic kidney disease. A kidney can either be donated from someone who has died or a living person.

Having a kidney transplant does not offer a cure but it is an ongoing treatment that requires you to take medicines to keep the kidney working. For many people having a kidney transplant offers the best treatment option as it gives the best chance of having a lifestyle similar to the time before you became ill. However, not everyone is suitable for a transplant, this depends on your medical conditions and general state of health.

Your kidney doctors and nurses will be able to advise you on kidney transplantation. There is no upper age limit for kidney transplantation but you do have to be physically fit. If you are frail, or have significant medical problems (for example heart disease or cancer), the risk of undergoing a transplant may be too great and therefore it may not be considered as a suitable treatment option. It is possible to have a kidney transplant before dialysis has started but as the average wait is about four years, having a transplant before dialysis is usually only possible if you have a suitable living donor. These are usually family members or close friends. There are a number of factors that determine whether a person is a suitable donor and most importantly, we have to be sure that they will not suffer any long-term harm by donating a kidney. We can provide you with information to guide you on whether someone (who is willing) would be a suitable donor.
Home therapies (dialysis at home) and self care

Taking responsibility for your own health and well being offers many benefits to people living with chronic kidney disease. Benefits include:

• Feeling in control of your condition and treatment
• Ability to live a more normal and better quality of life
• More independence and freedom
• Freedom from time consuming travel to and from the dialysis unit three times a week
• Increased knowledge, understanding and involvement which improves confidence and enables you to become an expert

Many people want to take control of their own dialysis treatment. Choosing to dialyse at home offers enormous benefits by giving you the flexibility, freedom and convenience of dialysing when it suits you. This means you are able to dialyse around your work, family and normal lifestyle.

There are two types of dialysis:

• **Peritoneal dialysis** uses the peritoneum (lining that surrounds your intestines). A special fluid that absorbs waste and excess fluid is run into the peritoneum, left in for a period of time then drained out

• **Haemodialysis** involves your blood being pumped around a dialysis machine through a filter where it is cleaned removing waste and excess fluid
You can choose to do either peritoneal dialysis or haemodialysis in the comfort of your own home. The full range of home therapy options available include:

- Continuous ambulatory peritoneal dialysis (CAPD)
- Automated peritoneal dialysis (APD)
- Assisted peritoneal dialysis
- Conventional home haemodialysis (3 times 4 hours per week)
- Enhanced frequency home haemodialysis (more than 3 dialysis sessions per week)
- Nocturnal (overnight) home haemodialysis

With home haemodialysis you can increase the number of dialysis sessions to more than 3 times per week, even daily if you want. Increasing the amount of dialysis you have generally means you feel better, live longer and can have a more flexible diet and fluid allowance.

Dedicated support and training is available for anyone wanting to go onto a home therapy and is provided by specially trained nurses.

**Unit based haemodialysis**

The Queen Elizabeth Hospital Birmingham has a dialysis unit on ward 301 and supports several satellite dialysis units. These include those located in; Aston, Great Bridge, Hereford, Worcester, Redditch, Woodgate Valley, Kings Norton and Smethwick and Llandrindod. We also plan to soon have units in Sparkhill and Llandindrod Wells.
You will be required to attend the dialysis unit 3 times each week for at least 4 hours. Staff on the dialysis unit will try to organise and plan your dialysis treatment near to where you live or work. However sometimes this may not be immediately possible. The kidney doctors and nurses will talk to you about your local kidney services. Consideration will also be given to your preferred days and start and finish times. Temporary arrangements may be made until your preferred days and times become available. Once you have a dialysis schedule it is important for you to attend your sessions on time.

The dialysis units try to be flexible around individual needs and will consider requests to change sessions but you will need to give the staff plenty of notice.

Conservative kidney management

Conservative kidney management (sometimes called supportive care) provides all aspects of kidney care support without dialysis treatment or having a transplant. Deciding not to have dialysis does not mean a “no treatment decision”. Conservative management tries to prolong the remaining kidney function, control symptoms of kidney disease and maximise health and well-being. It provides medical and practical care and gives support to patients, their families and carers. With good planning and communication unnecessary hospital admissions can be avoided. For further information please refer to the ‘Conservative Kidney Management’ information leaflet.
How do I choose?

Making a choice about kidney failure treatment is not easy. It is a very personal decision and will need to be guided by your lifestyle, support at home and other illnesses. We hold information days about kidney transplants and different types of dialysis to allow you to gain further information. In addition we have more detailed patient information leaflets and DVDs that you may find helpful. You are welcome to discuss treatment options with your kidney doctors and nurses in clinic, and we can put you in touch with ‘expert patients’ who can give you their views on particular treatment types.

Where can I find further sources of information?

Further information can be obtained from:


NHS Kidney Care [www.kidneycare.nhs.uk](http://www.kidneycare.nhs.uk)

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

Kidney Alliance [www.kidneyalliance.org](http://www.kidneyalliance.org)

Transplant Support Network [www.transplantsupportnetwork.org.uk](http://www.transplantsupportnetwork.org.uk)

Expert Patient Programme [www.expertpatients.nhs.uk](http://www.expertpatients.nhs.uk)

West Midlands Renal Network website [www.wmrn.co.uk](http://www.wmrn.co.uk)

NHS Choices [www.nhs.uk](http://www.nhs.uk)
Other Sources of Information

There are a wide range of local information leaflets that give further information. The following leaflets provide more in-depth information:

• Conservative Kidney Management
• What is Haemodialysis?
• Home Haemodialysis
• Peritoneal Dialysis
• Kidney Transplantation

A wide range of patient information leaflet and fact sheets are available through the University Hospitals Birmingham NHS Trust website and can be accessed via www.uhb.nhs.uk/patient-information-leaflets.htm
Useful numbers

Ward 301 (Acute) 0121 371 3096
Ward 301 (Chronic) 0121 371 3011
Aston Cross Dialysis Centre 0121 359 8427
Great Bridge 0121 557 5538
Kings Norton Dialysis Centre 0121 459 9002
Hereford Dialysis Centre 01432 274603
Woodgate Valley Dialysis Centre 0121 421 0090
Worcester Dialysis Centre 01905 721 940
Home Haemodialysis Team
Monday-Friday 09:00-17:00 0121 371 8340
CAPD
Monday-Friday 09:00-17:00 0121 371 8728
CKD Team Pre-dialysis
Monday-Friday 09:00-17:00 0121 371 8761
Please use the space below to write down any questions you may have and bring this with you to your next appointment.
The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm or call 0121 371 4323.