Conservative Kidney Management

Delivering the best in care

UHB is a no smoking Trust

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 advanced kidney disease to be able to make informed choices about their treatment to enable them to receive the very best care and live life as fully as possible.

This leaflet gives information about conservative kidney care to people with advanced kidney disease who may be unsure on whether to have dialysis treatment. It explains what may happen if you choose not to have dialysis and how the symptoms of kidney disease can be relieved.

What is conservative kidney management?
Advanced kidney disease means that both kidneys are damaged and cannot be repaired. Waste products that are normally removed by healthy kidneys slowly build up in the blood stream, becoming poisonous to the body. This build up of waste products causes the symptoms of kidney failure. When kidney function reduces to about 10% of normal function, dialysis or transplantation is sometimes offered to lessen symptoms and preserve life.

Advanced kidney disease is a life-threatening disease and difficult treatment decisions have to be made. Some people with advanced kidney disease decide that they do not want dialysis treatment.

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.
The aim of conservative kidney management is to:

- Treat and reduce any physical symptoms of kidney disease
- Protect and maintain remaining kidney function
- Support the achievement of the best possible quality of life
- Provide psychological, social, financial and spiritual support
- Plan for the future

Who is suitable for conservative kidney management?

Conservative kidney management is suitable for:

- People with advanced kidney disease who have chosen not to have dialysis treatment
- People who are likely to struggle with dialysis and where the treatment is unlikely to provide any real benefits because of frailty or having other medical conditions (for example serious heart and lung problems, or advanced cancer)
- People who no longer continue with their dialysis treatment or choose not to have dialysis after a kidney transplant fails

Some people feel that dialysis treatment will not improve the quality of their life. Haemodialysis can be very stressful and exhausting and can involve travelling to the hospital three times a week for four hours treatment and recovering from it.

The decision to choose conservative kidney management will be made following discussions involving yourself, your family, carers, doctors and nurses. It can be a hard decision to make and if you feel you are finding it difficult to decide on your treatment please talk to one of the doctors or nurses who will be able to offer advice.
What are the symptoms of kidney disease and how can they be controlled?

As the kidney function starts to fall you may develop the number of symptoms that can be helped. These include:

- Feeling tired and drowsy
- Itching
- Feeling sick
- Fluid retention, swollen ankles and breathlessness

Please let your kidney doctor or nurse know if you have any of these symptoms as they can be controlled by:

- Altering your tablets
- Adjusting your diet
- Checking to see if you are anaemic

How can I look after my kidney function?

Many patients who choose not to have dialysis live for months or even years after making this decision. A small amount of kidney function can go a long way to keeping you feeling well and free of symptoms. The remaining kidney function may slowly get worse but the rate at which this occurs can be reduced in a number of ways. Continuing medical support is important here, and will include:

- **Blood pressure monitoring** – controlling blood pressure limits further damage to kidney function

- **Diet** – eating a healthy diet can help you stay well when your kidneys are not working properly. Your diet should consist of regular meals and include fruit and vegetables daily.

- **Anaemia control** – anaemia is an important symptom of renal failure. Treatment of this can include iron tablets, Erythropoietin (EPO) injections, and blood transfusions if necessary.
• **Fluid restriction** – normally there is no need to restrict fluid intake since water tablets (diuretics) can be used to maintain the amount of urine you pass. Only if water tablets become less effective will a fluid restriction be needed to avoid too much fluid retention.

• **Salt** – not adding salt to your food can help with high blood pressure and helps the body retain less fluid. As your kidney function falls your appetite may reduce but the dietician can give you advice. Sometimes, potassium (a mineral found in the body) in your blood can become too high, and it may be necessary to restrict certain foods that contain lots of potassium. The dietician will explain if any adjustments are needed with your diet.

• **Drugs** – damaged kidneys can be prone to further damage by certain tablets. You should check with your kidney doctor or nurse before taking any new tablets.

Your care will be mainly delivered by a team of people from the local community led by your GP. Kidney doctors, nurses and other members of the kidney team will continue to be involved in your care and will work together with your GP, who may also involve other specialists such as the palliative care team or your local hospice. Palliative treatment gives relief from the symptoms of the disease but does not cure it. The aim of palliative care is to keep you active and independent for as long as possible.

**Planning for the future**

Shared care planning is an important aspect of conservative kidney management. It helps you, your family and carers think about how and where you want to be cared for when you become more unwell. This enables you to develop an agreed plan of care based on your personal needs and future wishes with your kidney doctors and nurses.
How long will I live?
This varies for each person. There are many things that affect how long you live. If you have other medical problems, it is quite possible that the length of your life would not be changed by having dialysis. If there is a reasonable amount of kidney function left, this may last for a number of years. On the other hand, if there is hardly any kidney function left, survival is likely to be no more than a few weeks. Your kidney doctor will be able to discuss this with you and explain the things that can affect this.

Can I change my mind?
You can change your mind and your kidney doctor and nurse will support you, however starting dialysis in an unplanned way can be difficult.

Where can I find further sources of information?
Further information can be obtained from:
The National Kidney Federation www.kidney.org.uk
West Midlands Renal Network website www.wmrn.co.uk
NHS Choices www.nhs.uk
More information about conservative management of established kidney failure can be found in a Kidney Research UK publication, Choosing not to start dialysis. This can be downloaded from the website www.kidneyresearchuk.org – click ‘information, then go to ‘factsheets’. Alternatively it can be ordered by calling the helpline on 0845 300 1499.
Useful numbers

Most of the symptoms you may have can be managed at home. Your GP and primary care team have been given all the information they should need to be able to support you. If they or you need any help or further information our contact details are provided below.

**Dr Ferro’s Secretary**
0121 627 2528 (09:00–17:00 Monday–Friday)

**Renal Community Team**
0121 627 5752 (09:00–17:00 Monday–Friday)
The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk or call 0121 627 7803

Renal Unit

Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston,
Birmingham, B15 2WB
Telephone: 0121 627 2000