



Treatment of Kidney Failure without Dialysis / An Introduction to Conservative Management

Introduction

The aim of this leaflet is to provide you with as much information as we can about what might happen to you if you decide not to have dialysis. We will explore the symptoms of kidney failure and how they can be best managed without dialysis and hope to answer some of the difficult questions you may have.

Chronic kidney disease means that both kidneys have been gradually damaged to beyond repair. The chemical waste products that are normally removed by healthy kidneys gradually build up in the blood stream, becoming toxic to the body. This is what causes the symptoms of kidney failure.

When the kidney function reduces to about 10% of normal, this is referred to as End Stage Kidney Failure and is when dialysis is made available for those who wish to have it. Some may also have the option of a kidney transplant depending on existing health problems.

Dialysis can be a life saving treatment, it can improve quality of life and life expectancy for some people with End Stage Kidney Failure, however the treatment is demanding both physically and emotionally it is time consuming and requires long term commitment and lifestyle changes.

Dialysis only partly replaces some of the kidney's functions it may not benefit other health problems. The treatment can make some health problems worse and may not improve quality or length of life. It is important for you to have a clear understanding of your individual illness and the likely advantages and disadvantages to having dialysis. Choosing not to have dialysis will eventually lead to the end of your life although many people will die from existing health problems or old age. The renal team are here to support you, your family and carers through your journey taking into account your individual problems, circumstances and concerns.

What is conservative kidney management?

Your renal team will continue to look after you if you decide not to have dialysis. Conservative management aims to protect and preserve your remaining kidney function and to prevent or treat related symptoms.

How can I protect my remaining kidney function?

Many people who choose not to have dialysis continue to feel well and report being free from any major symptoms as they approach end stage kidney failure. The rate of kidney decline can be reduced by a number of means, most importantly by keeping your blood pressure well controlled.

We advise that you continue to take your regular medication and report any changes made or additions of over the counter tablets to a member of your team. It is also important to avoid becoming dehydrated as this will put extra strain on your already struggling kidneys, if vomiting and diarrhoea bugs do not clear up quickly please seek medical advice without delay.

Managing Symptoms of Kidney Failure

Anaemia / Tiredness

Anaemia or lack of red blood cells is very common in patients with kidney failure and it generally gets worse as they kidney function declines. We are able to offer various treatments for renal anaemia which may include infusions, injections and tablets.

Poor Appetite

We would like you to continue with a healthy balanced diet as such as possible but understand that your appetite may decline as your kidney failure progresses; some people report a nasty taste in their mouths which can put you off your food. Your renal dietician can advise on managing poor appetite and offer tips to help avoid weight loss.

Nausea and Vomiting

This can also have a detrimental effect on your appetite therefore we need to know about any episodes of vomiting and periods of nausea as we are able to suggest medication which may help alleviate these symptoms.

Itch / Dry Skin

Many people report dry itchy flaky skin over time, this can be helped with the use of oil based soap substitutes, and certain creams and we could also prescribe anti itching tablets if required.

Fluid Retention

Water tablets (diuretics) are prescribed to help maintain a stable fluid balance in the body by pushing the kidneys to produce urine. These tablets are regularly reviewed and altered in dose and strength and if found to be becoming less effective a fluid restriction may be suggested.

Pain

Kidney failure itself does not usually cause pain but if pain is a problem for other reasons we can advise on suitable pain relief medication. It is important that your kidney team are aware of all of your medications particularly any that you buy over the counter as some of these can be harmful to your remaining kidney function.

Can I really choose not to have dialysis?

YES

Choosing not to have dialysis is a personal decision and is reached over a period of time following discussions with those close to you and your renal team.

Occasionally the choice of not having dialysis treatment is a medical decision made by the renal team especially if you have existing health problems that outweigh the benefits of dialysis.

Some people with chronic kidney failure have a very stable kidney function, and may never actually need dialysis. We also know that many people on conservative kidney management programmes die from their existing medical conditions or old age and not because of their kidney failure.

It is important that you talk things through with those close to you; members of your renal team are also available to discuss concerns as they arise and are happy to talk to your family and close friends with your consent if you are finding it difficult to discuss any matters.

Will you continue to support me?

YES

You will continue to see the nephrologists (kidney doctors) and renal nurses regularly in the clinics and home visits may be offered if these become too burdensome to attend.

You will also be supported by other members of the multidisciplinary team as required, including the anaemia team, dieticians, occupational therapists, and social workers.

Your care will be coordinated both in the hospital and community setting we will advise your GP and primary care nursing team of your decision not to have dialysis and keep them up to date with your progress. This teamwork is vital in ensuring that as your health deteriorates we have links available with palliative care, hospice services and Macmillan nursing teams depending on your preference.

Can I have a trial of dialysis?

A trial of dialysis can be risky and disappointing.

You will require some physical preparation for the treatment to enable us to perform the dialysis through either an arterio venous fistula operation in your arm which takes many weeks of preparation and may involve a stay in hospital, or placement of a catheter into one of the large veins in your neck.

Sometimes a trial of dialysis is appropriate if it is not clear whether you will be helped by dialysis. Your kidney doctor would assess whether you were benefiting from the treatment over a set period of time, usually a few weeks. Based on these assessments the team will help you decide whether to continue, it will always be your informed decision to stop.

Once you have started dialysis it is often more difficult to stop even if you feel unwell on the treatment. This is because in some patients the kidneys stop functioning completely soon after starting dialysis.

Dialysis may even cause serious complications and bring about an earlier death than expected for some people.

Can I change my mind?

We hope that any decision for conservative kidney management is made as it is the best option for preserving quality of life for as long as possible.

We understand that people may change their minds and will support you onto dialysis wherever possible. As previously mentioned some pre-existing medical conditions could make dialysis a very dangerous option and it may not even be technically possible.

If the decision to start dialysis is delayed until you are very symptomatic and unwell, starting treatment becomes much more hazardous and complicated, with any potential benefit being harder to achieve.

How long will I live without dialysis?

This varies for each individual and can range from a few days or weeks for people whose kidneys have completely failed to several months or years for those whose kidneys still function in some part.

It also depends on factors including the rate of decline of kidney function, other existing medical conditions and general wellbeing. Talking to your kidney doctor can give you more of an understanding of your particular situation, although it is impossible to be very accurate they may be able to give you a rough estimate of life expectancy.

Where can I die?

You will have the opportunity to discuss your end of life care wishes. This will include being cared for and dying at home with support from community palliative care and district nurse services in conjunction with your GP. You will have the opportunity to access local hospice care or you may even choose to come into hospital. The important thing is that you discuss your wishes with your family and carers, if you indicate your preferences those caring for you will have a greater understanding of your wishes and be able to honour them wherever possible.

What will it be like at the end?

Conservative management is aimed at achieving good symptom control and this aim continues as you approach the end of your life. Those looking after you, district nurses, palliative care or hospice services will continue to address your symptoms and try to relieve them. In the final stages of life oral medication can be replaced with infusions as appropriate.

Death due to kidney failure is a progressive process and towards the end you may become drowsy, often slipping into a coma before death, which is usually peaceful and pain free.

Making end of life arrangements

Many people do not like to think about the arrangements that need to be made before they die. However, you may like to consider the following:

- Making a will
- Making a list of names of people you would like to be contacted and told of your death
- Making a list of other important contacts, including your bank, insurance policies, pension plans and other legal papers
- Writing a statement about your wishes for the funeral service, burial or cremation

Useful Telephone numbers:

Advanced Kidney Care Team 0121 424 2677

Dieticians 0121 424 0675

Occupational Therapist 0121 424 1472

You can access the National Kidney Federation via the internet. E-mail address:

www.kidney.org.uk

References

Marshall K, Hodson C, Da Silva Gane M, Warwicker P, 2005. What I tell my Patients about conservative management of their established renal failure British Journal of renal Medicine 2005; Vol 10 No 4

Alston H, Farrington K 2012. What I tell my patients about conservative kidney management British Journal of Renal Medicine 2012; Vol 17 No 3

The Richard Bright Renal Unit, North Bristol NHS Trust, Supportive Care for Renal Patients with Established Renal Failure (*ERF) Version 3 May 2008

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