

What is the right choice for me?

Choosing supportive care
instead of dialysis

Sussex Kidney Unit



Information for patients and families

Introduction

This leaflet provides information about supportive care that can be offered to those with advanced kidney disease who are unsure whether they want to have dialysis, which is a complex form of treatment. It explains what may happen if you choose not to have dialysis and how any symptoms of kidney disease that you may experience can be relieved.

Advanced kidney disease means that both kidneys are damaged and cannot be repaired. Waste products slowly build up in the blood stream, becoming poisonous to the body and causing the symptoms of kidney failure. When the kidney function falls to about 10% of normal function, dialysis or transplantation are treatment options which are commonly used to improve symptoms and to prolong life. Advanced kidney disease is a life threatening illness and difficult treatment decisions have to be made.

Dialysis treatment only partly replaces some functions of the kidney and may not benefit other health problems. The treatment may make some of them worse and may not improve your quality of life. In such situations it is important for all concerned to have a clear view of the likely advantages and disadvantages of undertaking dialysis treatment. This should take account of your particular problems, circumstances and concerns. Reaching this point usually involves a good deal of discussion over a period of time between you, your relatives and carers and the renal team.

Ultimately if dialysis is not started, end stage kidney disease will eventually lead to death.



What is supportive care?

Supportive care (also called maximum conservative 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 option'. Supportive care aims 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 and unwanted hospital admissions can be avoided.



The aim of supportive care is to:

- Treat and reduce any physical symptoms of kidney disease
- Protect and maintain remaining kidney function
- Support the best quality of life possible
- Provide psychological, social, financial and spiritual support
- Planning for the future which may include making decisions about treatment and care at the end of your life.

Who is suitable for supportive care?

Supportive care is suitable for:

People who have 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 heart and lung problems or advanced cancer).

Some people feel that dialysis will not improve their quality of life.

Haemodialysis can be very stressful and tiring, involving having to travel to hospital three times a week for four hours treatment. It can be a burdensome experience for some people if there is no real benefit or improvement to their quality of life.

The decision to choose supportive care will be made following discussions involving yourself, your family, carers, doctors and nurses. It can be a hard decision to make and if you are finding it difficult to decide please talk to one of the nurses or doctors who will be able to offer advice or arrange counselling support.

How can I look after my kidney function?

Many patients who choose not to have dialysis live for months or even years after making the decision. A small amount of kidney function can go a long way to keeping you feeling well and free of symptoms. Your remaining kidney function may slowly get worse but your medical team can recommend a variety of treatments that can help reduce the speed of this.

These include:

Blood pressure treatment

Controlling your blood pressure limits further damage to your kidneys. It is very important to take your blood pressure medication to help protect your kidney function.

Anaemia treatment

Anaemia is a common symptom of kidney failure. Treatment of this can include iron tablets or infusions, Erythropoietin (EPO)/Aranesp injections, and blood transfusions if necessary.

Diet

It is important to eat a healthy diet and be well nourished. Reducing your salt intake is very important to help control your blood pressure and any fluid retention. As your kidney function gets worse it may not be able to control the balance of certain minerals in your body called potassium and phosphate. If this happens a dietitian will be able to give you tailored dietary advice to help control these. You may also find that as the waste products increase in your blood you go off your food. If this is a problem please let your doctor or nurse know so they can refer you to a dietitian for practical advice on how to increase your intake.

Diabetes treatment

If you have diabetes good blood sugar control can help limit further damage to your kidneys. Your GP, practice nurse or diabetic nurse can help with this by giving you advice on how to best manage your diabetes.

Fluid restriction

Normally there is no need to restrict your fluid intake since water tablets (diuretics) can be used to maintain the amount of urine you pass.

Occasionally people find that the water tablets become less effective and they continue to retain water and notice their legs or feet have become puffy. If this happens you may need to be careful how much you drink. Your doctor or nurse will tell you if you need to limit the amount you drink.



Drugs

Damaged kidneys can be prone to further damage by certain tablets including over-the-counter medications and herbal remedies. You should check with your kidney doctor, nurse or pharmacist before taking any new tablets to ensure that they are suitable for people with kidney problems. In general we recommend that you do not take any alternative or herbal remedies.

If you are suffering any unpleasant side effects from your medications please do not stop taking them, let your medical team know so they can try a different type that may suit you better.

Will it affect how long 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 or not having it. 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 only minimal 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.

Will I experience pain when I am dying?

Death from kidney failure is usually painless and peaceful, some people may experience pain from other illnesses but there are many very effective treatments available for controlling pain in these circumstances.

Can I change my mind?

Yes. You can change your mind to have dialysis at any point and your kidney doctor or nurse will support you. It is however important to say that starting dialysis in an unplanned manner can be more difficult and be harder on you both mentally and physically. Should you opt to have dialysis and then decide it is not the right choice for you we can also support you and help you tell your family.

The key is to make the right choice for you.



Where can I find further sources of information?

British Kidney Patients Association

www.britishkidney-pa.co.uk

Tel: 01420 541424

Useful numbers

Renal Outpatient Department 01273 664559

Main Dialysis Unit 01273 696955 extension 64605

Renal Ward 01273 696955 extension 64057

Renal Counsellors 01273 696955 extension 64097

Chaplain specialising in renal care:

Brighton 01273 696955 extension 64122

Princess Royal Hospital 01444 441881 extension 8232

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