

Kidney Health Information

Choosing not to start Dialysis

Does everyone choose to dialyse?

For many people with advanced kidney failure, dialysis treatment can greatly improve their quality of life. However, the treatment may be demanding and time-consuming and it is usually necessary to make lasting changes to lifestyle. Although it is often possible for these patients to adjust and still lead a fulfilling life, dialysis is not a cure-all. The treatment only partly replaces some functions of the kidney and it does not benefit other health problems; indeed the treatment may make some of them worse. Because of this, dialysis may not improve the quality of life for some people. The need to change lifestyle can also prove an added burden. This is usually when patients have other serious medical conditions or are generally frail and dependent.

In such situations it is important for all concerned to have a clear view of the likely advantages and disadvantages of dialysis treatment for each individual patient. This should take account of each patient's particular problems, circumstances and concerns. Reaching this point usually involves a good deal of discussion over a period of time between patient, relatives and carers and the renal team.

During the course of this, some patients make it clear that they choose not to start dialysis. Sometimes this is because of long-held beliefs about quality of life in such situations, sometimes the decision is reached after consideration with loved ones of the available choices, sometimes it is on the advice of the renal team.

So I can decide not to have dialysis treatment?

Yes. You have the right to decide not to start dialysis if you feel that the burden would outweigh the benefits and reduce your quality of life. But you need to discuss the issue thoroughly with those close to you and with members of the renal team looking after you.

Who can I talk to if I decide not to start treatment?

It is important for you and your family to talk these matters through with members of the renal team, because this is a decision that usually needs to be made together. Although each renal unit is slightly different in terms of its organisation, there will always be members of staff – from a range of professional backgrounds – who have the necessary experience, knowledge and skills to explore with you what starting dialysis involves and what it would mean not to start dialysis. They can also offer emotional support to you and your family whatever the decision. In the first place you can raise any matter of concern with one of the doctors or specialist nurses during a clinic visit. They

may suggest involvement of other team members such as the renal social worker or renal counsellor.

Will the doctors be supportive if I choose not to have dialysis treatment?

Of course. All the doctors you see in clinic will be supportive, and willing to discuss this issue with you. Their aim is to help you decide what is right for *you*.

What if I cannot decide?

Sometimes it is difficult to decide whether dialysis will benefit an individual and outweigh the burden. If this is your situation, the doctor may suggest you have a trial period of dialysis, usually a few weeks. During this time you, your family and the renal team will see how dialysis is affecting you, both medically and psychologically. The doctor and other members of the team will then be able to talk with you and decide whether or not it is advisable for dialysis to continue.

It is very hard to know how to talk to my family and friends. Can you help?

Many people find it difficult to talk about such matters to those who are close to them. They are often concerned that they might upset their relatives, or are worried how they will react. With anything that is difficult it is always best to talk openly and honestly. You may find it useful to involve the doctors, specialist nurses or other members of the renal team. If there is a particular

member of the team you have found easier to talk to, this may be the person you prefer to contact.

Is deciding not to have dialysis suicide?

Many religions believe individuals have the right not to accept medical treatment, including dialysis, if they feel it will not help them. You may wish to speak with your religious advisor if you have any concerns about this.

Are there alternatives to dialysis?

- **Medical treatment** It is important to know that there are alternative treatments to dialysis. Just because you are not having dialysis, it does not mean that you cannot have active treatment for your kidney problem. Treatment aims to protect and maintain remaining kidney function and to prevent or treat symptoms of kidney failure. There are aspects of kidney failure which dialysis does not help, but for which there are well-established treatments useful whether or not patients are being dialysed, such as the treatment of anaemia.

The main purpose of dialysis is to remove waste products and excess fluid. Parts of this function can often be managed in other ways, and in some cases the effects of having kidney failure can be reduced.

- **Measures which can help to preserve your remaining kidney function** A small amount of kidney function can go a long way to keeping you feeling well and free of major symptoms. The natural tendency is for

remaining kidney function to get slowly worse, but the rate at which this occurs can be reduced – by a number of ways. The most important of these is to ensure good control of blood pressure. Damaged kidneys are more prone to further damage and some drugs can cause major problems. These include remedies that can be bought over the counter, such as non-steroidal anti-inflammatory agents (e.g. Brufen or Nurofen), which are used for treating arthritis and general aches and pains. You should check with one of your doctors before taking any new medicines. Avoiding dehydration is also important, especially during episodes of illness such as diarrhoea and/or vomiting, which may be going round the family.

- **Treatment of anaemia** Anaemia is very common in patients with kidney failure and tends to become more severe as the problem progresses. Normal kidneys produce a hormone called erythropoietin (EPO), which stimulates the bone marrow's formation of red blood cells. Damaged kidneys produce less EPO, and that causes anaemia. Shortage of iron may add to the problem. Anaemia accounts for many of the symptoms of kidney failure, particularly tiredness and weakness. EPO is a very effective treatment for anaemia in kidney failure and needs to be given once or twice weekly by injection, initially by the district nurse but subsequently by patients themselves or by their carers.

Is there a need for a special diet?

The aim is to recommend a healthy, varied and enjoyable diet but some modifications to the diet may be helpful. Generally it is advisable not to add salt to meals, as too much salt can cause you to retain fluid and have difficulty with blood pressure control. Salt substitutes are not a good idea; they usually contain potassium, which often needs to be restricted as well. Foods containing excess potassium such as bananas, oranges, and chocolate should be used as treats rather than as regular items of diet. Other changes in the diet might be helpful in particular circumstances. These might range from the avoidance of too much protein to the prescription of dietary supplements for those patients who have a reduced appetite. Expert assessment by a dietician, who is an important member of the renal team, is normally necessary before such recommendations are made.

Is there a need to restrict my fluid intake?

Salt restriction can be of great benefit. Normally there is no need to restrict the amount of fluid you drink, since diuretics (water tablets) can be used – with the doses being increased as required to maintain a reasonable urine output. Only if water tablets become less effective will some restriction of intake be necessary. Everybody is different though, and your doctor will advise you if this is needed.

How can I control other symptoms?

As kidney failure progresses, other symptoms may need to be prevented or controlled. Your doctors can prescribe treatments such as anti-emetics (anti-sickness medicines) and anti-pruritics (medicines which help to alleviate itching) should you need them. Kidney failure does not normally cause pain.

How will my care be organised?

Your care will be delivered by a team of people from the hospital, the community and your home. Your medical care will normally be managed by your renal doctors together with your GP, whose role – like that of the district nurse – may increase as kidney failure progresses. The GP or district nurse may also involve other specialists such as the Palliative Care Team who work in the hospital, the community and your local hospice. Palliative treatment gives temporary relief from the symptoms of a disease but does not cure it, and the aim of palliative care is to keep you active and independent for as long as possible.

Control of symptoms may be required when kidney failure is advanced. The renal specialist nurses and other key team members, such as the renal social worker and district nurse, have vital roles in the planning and/or delivery of care, in providing ongoing support and in acting as valuable points of contact. Dieticians, pharmacists, counsellors, community social workers and carers can also play their parts. Teamwork is essential.

How long will I live if I do not start dialysis?

This varies from individual to individual, and depends on many factors. If a patient has other serious medical problems then it is quite likely that their outcome will not be affected by the decision not to dialyse. The other main consideration is just how much remaining kidney function an individual has left when the decision not to dialyse is made. If there is a reasonable amount then with the right attention this might last for a number of years. On the other hand, if an individual does not have any kidney function at all, then survival is likely to be no more than several weeks. Most cases of course fall in between these two extremes, so you will appreciate that the answer to this question depends completely on an individual's circumstances. You should raise this question with your doctor who will be able to give you his/her opinion on your particular situation and discuss these important issues with you.

Will I have a choice of where I die?

Many people prefer to die at home, where they feel more comfortable and can be in familiar surroundings. This is especially so when there is help from family, friends or carers, which can often be supported by community services including palliative care. In many areas, hospice care is well developed and in these circumstances you may wish to receive such support. A hospital admission may be another option for some people. These issues should be discussed and plans made to support you and your family.

Should I write down what I want to happen?

It is useful to write down what you would like to happen. It is also possible for the information to be documented on your hospital medical notes so it is clear to all of the medical team the plans and decisions that have been made. The doctor will ask you from time to time whether you would like any changes made to the plan.

Is there anything else that I need to know or should do?

Many people do not like to think about arrangements that need to be made before they die, but all of us would be advised to have made decisions about the following:

- Making a will
- Making a list of names, addresses and telephone numbers of family, friends and business associates whom you would like to be contacted and told of your death
- Making a list of other important contacts, including the location of your bank, other financial accounts, insurance policies, pension plans and other legal papers
- Writing a statement about your wishes for the funeral service, burial or cremation
- Collecting any written messages that you may wish to leave for loved ones

What if I have questions that you have not covered?

It is likely that you will have other questions in addition to those in this factsheet.

- If you have any medical concerns, please talk to the doctors
- If you require any more information about legal matters, such as writing a will, you need the advice of a solicitor
- If you have concerns about support for you and your family at any time, please feel free to contact any member of the renal team involved in your care

You might find it helpful to keep a list below of the main contact telephone numbers you find most useful.

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YOU MUST CONSULT YOUR OWN DOCTOR**

Kidney Research UK, Kings Chambers, Priestgate, Peterborough PE1 1FG

Kidney Health Information telephone number: 0845 300 1499

Or text keyword KIDNEY with message to 0778 620 0505

Or email: kidneyhealth@kidneyresearchuk.org

If you would like to make a donation please call free on 0800 783 2973