

# Withholding and withdrawal from dialysis (more info)

When renal failure approaches, you can decide **not** to have dialysis. This page describes why occasionally this may be the best option for some people, and what the alternatives are. This is a longer and quite detailed discussion. Too much detail? [Shorter and simpler information is available.](#)

## **Introduction: who should read this?**

Most information that you will read about dialysis is very upbeat and optimistic. You may well have seen pictures of people on dialysis who work for 12 hours each day and climb mountains in their spare time. Dialysis is certainly a lifesaving treatment for people who could do these things before they needed dialysis. You will be able to guess (or maybe already know) that the reality isn't as good as this for everyone.

In the early days of dialysis most patients were young and otherwise healthy, and some of these patients have lived for decades. Now that many more people can be offered dialysis, it is not always clear that it will prolong life by very much, and dialysis has never been an easy treatment for even the fittest people.

## **Why is dialysis difficult for some people?**

Those who find dialysis particularly difficult usually have other serious illnesses as well as kidney disease. Heart or lung disease, or severe narrowing of arteries to the legs, are common examples. Old age itself is not a barrier to feeling well on dialysis, though older people are more likely to have other diseases.

Dialysis, especially haemodialysis, can be stressful and exhausting. Most of three days each week may be spent travelling to and from dialysis, receiving the treatment, and recovering from it. Heart disease and some other conditions may make the treatments particularly difficult for some. Patients who are easily confused (e.g. suffering from dementia) may find dialysis frightening or confusing, and may have difficulty with necessary medicines and restrictions.

## **How long can I expect to live if I have dialysis?**

There is a lot of information that can help here, but no way of telling exactly what

will happen to any one person. Our own figures are not very different from other similar centres, but they can only give a very rough estimate that must be combined with your own doctors' opinions.

<b>Survival on dialysis</b>	
<b>LOW RISK PATIENTS</b> Under 70 years old with no other illnesses	90-95% are alive after 2 years of treatment (more if younger)
<b>MEDIUM RISK PATIENTS</b> 70-80 years old, or under 70 years old with one other serious illness*	2 out of 3 are alive after 2 years of treatment
<b>HIGH RISK PATIENTS</b> Over 80 years old, or any age with two serious illnesses*	1 in 3 are alive after 2 years of treatment

\* "Serious illness" here means having had a heart attack or angina; or a stroke; or diabetes; or narrowing of arteries causing claudication or an amputation.

In the 'high risk' group in Edinburgh in 2000-2001, there was a 50:50 chance of living more than 14 months. However all patients are different. Your doctors may be able to say whether the risk for you is higher or lower. Some of those who live for longer than 14 months survive for several years.

Sometimes it is obvious that dialysis is not going to prolong life, only reduce the quality of the remainder of a patient's life.

### **Keeping well without dialysis: "Maximum Conservative Management"**

Experience has shown that many patients who choose not to have dialysis can live for months or even years after making this decision. Continuing medical supervision is important here, and will include:

- Diet - patients who are not going to receive dialysis will benefit particularly from attention to what they eat. This is an important part of management.
- Anaemia management - anaemia is an important part of the symptoms of renal failure. Treatment of this can include all the things used to treat anaemia in patients receiving dialysis, including erythropoietin (EPO)

injections, and blood transfusions if necessary.

- Blood pressure – controlling blood pressure limits further deterioration of kidney function
- Symptom control – many treatments are available to control symptoms that may occur. Important ones are described in the next paragraph.

## **What symptoms might I get?**

Tiredness and drowsiness are major symptoms. Feeling sick and being sick can be problems later on, but this can usually be controlled by diet and by medicines if necessary. Fluid build-up is another common problem, which can usually be controlled with tablets and restriction of salt intake.

Dying with renal failure is usually peaceful and it is not painful.

## **Do many people decide not to have dialysis?**

Yes. An increasing number are making this decision well in advance and therefore living a very long time. Often they die of something else before dialysis would have been needed.

For patients already on dialysis, surveys in several countries have shown that stopping dialysis is quite a common cause of death. These are almost always people who have developed other serious illnesses after starting dialysis.

## **I have kidney failure and I don't think I want dialysis. What should I do?**

Often if doctors mention dialysis to you they will tell you if they think it will be very difficult for you. If they have not discussed this, you should ask. It is also important that you discuss it with your family and close friends.

## **I'm not sure. Could I try dialysis?**

A “**trial of dialysis**” is possible but can be risky and disappointing. You will go through the disruption, inconvenience and dangers of dialysis, and may end up feeling worse and in hospital. If you don't do well it will all seem very disappointing. It is then often an even more difficult decision to stop treatment, even if you don't feel well on it. Dialysis may cause serious complications and bring about an earlier death for some people.

Some people disagree with this view and commonly recommend a trial of dialysis. We would probably recommend it to a patient if we thought that they were being unnecessarily pessimistic about how they would feel on dialysis. But in the end it would be your choice whether you followed this advice or not.

### **Do you ever refuse to give dialysis?**

It is very rare for this question to arise. Sometimes it is obvious to all involved that dialysis would be unhelpful. For example the patient is likely to die very soon from another condition, or dialysis may worsen quality of life with very little prospect of gain. Almost always the patient understands this when they are capable, but frequently this question arises for patients who are not well enough to be able to make their own decisions. The decision then needs to be discussed carefully with family or carers. Occasionally family members may have unrealistic expectations about what dialysis might achieve.

In some countries it is unfortunately not possible to provide dialysis for everyone who could benefit from it. This is not the case in most wealthy countries in western Europe or North America, but is common elsewhere in the world. On the other hand, some people believe that in some western countries dialysis is used too much, and that some patients are being given only slightly longer lives, and an unhappy death.

Britain has lagged behind other European countries in providing dialysis places, but numbers have expanded hugely over the last 20 years. No units operate an age barrier or other fixed limitation on who can be treated. Every patient is considered individually.

### **What does the law say?**

The law in Britain permits anyone to refuse treatment that might keep them alive, as long as they are able to understand the decision that they are making. If a patient is not able to make their own decision, staff will usually try to find out what the patient's views would have been if it had been possible to ask them. This does not mean that it is up to the relatives to decide. The likely benefits from the treatment will also be considered. The law in Scotland differs a little from that operating in England and Wales, but the broad principles are similar. Many countries have a similar legal framework.

## Implications for staff

In discussing the options for people with severe kidney failure, the 'no dialysis' option should always be included. If a patient decides that they do not want to have dialysis, and makes that decision in a rational manner after discussion and thought, it is appropriate to be supportive of their decision. Resources should be available to support patients in these circumstances. Continuing involvement of the renal team is almost always appropriate. Joint care with palliative care services is sometimes appropriate.

## Summary points

For some people with other serious illnesses as well as renal failure, dialysis may make little difference to how long you live
Dialysis can be very difficult for some people
In these circumstances, 'no dialysis' may give a better quality of life than dialysis
Every patient deserves careful discussion

## Further information

We have a [shorter page](#) giving a simpler summary of this information.

- [Choosing not to start dialysis](#) from the NKF(USA).
- [Deciding to stop dialysis](#) from the NKF(USA).
- The [General Medical Council](#) of Great Britain published a guideline in 2002 on withholding and withdrawing life-sustaining treatments which has since been updated at least a couple of times. Their page on [Withholding and withdrawing life-prolonging treatments: good practice in decision making](#) is long and written for a medical readership but gives a balanced view of the ethical and legal considerations. If you cannot find the document immediately, go to 'search' and type in 'withdrawing'

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