What I tell my patients about conservative management of their established renal failure

A multidisciplinary approach (where healthcare and other professionals from different fields treat you) is essential to provide a comprehensive and successful programme dedicated to the needs of patients with established renal (kidney) failure, who are to be managed conservatively (that is, without dialysis or a transplant). In this article, we have concentrated on the conservative management of patients who have never been dialysed, rather than the care of patients choosing to withdraw from dialysis.

These issues have also formed an important part of the government's recent *National Service Framework for Renal Services* (part two), which sets the standards of care for renal patients. The standards in this document stress the importance of providing access to information that enables people to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life. It also encourages drawing on the expertise of palliative care teams.

Advances in science and medicine have resulted in a greater understanding of many diseases and have led to the development of new treatments. As a result, patients are living longer, often with other diseases and, when faced with established renal failure, many may not wish to embark on dialysis. Others may not be physically or mentally able to cope with such therapy. For these groups of patients, conservative management is a valid and widely acknowledged treatment option.

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There is confusion between rationing of dialysis, which is defined as limiting access to an expensive medical treatment to save money, or in times of shortage (akin to rationing during the War), and rational dialysis, which is the attempt to limit the use of dialysis therapies when they would not improve the quality of a patient's life, or perhaps even make it worse

What is established renal failure?

Established renal failure describes an advanced and irreversible decline in renal (kidney) function. Kidney replacement therapies, such as dialysis or kidney transplantation, are not usually required nor even considered until kidney function has fallen to 10–15% of normal. This is sometimes known as 'end-stage renal failure' (ESRF) but is more appropriately referred to as established renal failure (ERF). Doctors also refer to this level of kidney impairment as Stage 5

Table 1. Stages of chronic kidney disease

Stage	Description	Glomerular filtration rate (GFR)
Normal kidney function	Healthy kidneys	90 ml/min/1.73 m^2 or more
Stage 1	Kidney damage with normal or high GFR	90 ml/min/1.73 m^2 or more
Stage 2	Kidney damage and mild decrease in GFR	60–89 ml/min/1.73 m^2
Stage 3	Moderate decrease in GFR	30–59 ml/min/1.73 m^2
Stage 4	Severe decrease in GFR	15–29 ml/min/1.73 m^2
Stage 5	Kidney failure	Less than 15 ml/min/1.73 m^2

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chronic kidney disease (the stages of kidney disease are determined according to the rate at which your kidneys function, called the glomerular filtration rate – see Table 1, page 15 and Figure 1). Established renal failure currently affects between 400 and 1,000 people per million in Europe.

What is 'conservative management' of established renal failure?

Conservative management is treating and controlling symptoms of established renal failure, without using dialysis or transplantation. It provides medical, psychological and practical care for both the patient and their immediate family, and nurtures discussion and planning of end-of-life issues.

In our unit, after an initial medical assessment, patients are referred to a liaison team, led by a senior nurse and a renal counsellor. Usually patients are referred well before they reach the stage of established renal failure.

The roles of the team include providing information, education, assessment of each patient's level of understanding of their illness and its consequences, assessment of their functional capacity, level of dependency, level of family and social support, and assessment of their perceived needs and expectations. A great deal of discussion is required, over a period of time, to be able to reach a decision regarding the conservative management of renal failure.

There is no obligation to undertake dialysis therapy ... and such a decision will be fully supported

The team are readily accessible for help and advice. Often the patient and their family find that there is one particular member of the team to whom they find it easier to talk, and this may be the person they prefer to contact.

Who makes the decision to choose conservative management?

The decision to opt for conservative therapy, rather than dialysis, will be made following discussions involving yourself, your relatives, carers, doctors, nursing staff, counsellor and other renal liaison staff and, at times, with the primary care team (your GP and district nurses). Some may feel there is an ethical or moral dilemma and may wish to discuss their decision with a spiritual leader. For others it will be a natural decision reflecting their wishes, or a change in direction after a lot of previous medical treatment.

Whatever the scenario, you should understand that there is no obligation to undertake dialysis therapy if your expressed wish is for conservative management, and such a decision will be fully supported by the renal team.

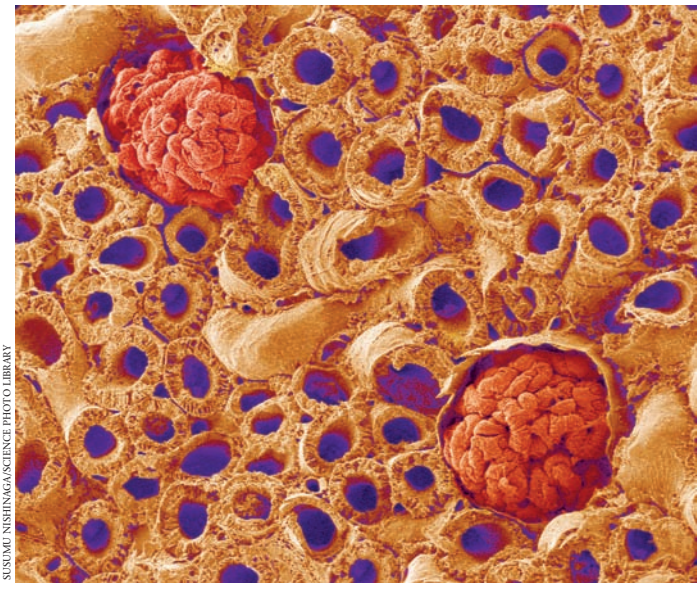

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Figure 1. If you have established kidney disease, glomerular filtration rate (GFR) is the best test to measure your level of kidney function and determine your stage of kidney disease. It is a measure of the rate at which the filtering units of the kidney, known as glomeruli (above, red), filter the blood. Your doctor can calculate it from the results of your blood creatinine (a waste product that comes from muscle and is filtered by the glomeruli), together with your age, race, gender and other factors

What if I cannot decide, will someone be able to help me?

It can be a daunting decision and if you feel unable to choose which route to take, the team can advise you.

Some people may also find it difficult to talk about such matters with those close to them. With your consent, the liaison team will always be happy to talk with your family and close friends.

Could dialysis be withheld because I am too old, or because of rationing?

Patients are often concerned regarding the availability of dialysis, and it is true that in some parts of the country the capacity to offer a choice of dialysis treatments is limited, but the decision between conservative management and dialysis is always made with the aim of achieving the best treatment for the individual.

There is confusion between rationing of dialysis, which is defined as limiting access to an expensive medical treatment to save money, or in times of shortage (akin to rationing during the War), and rational dialysis, which is the attempt to limit the use of dialysis therapies when they will not improve the quality of a patient's life, or perhaps even make it worse.

Dialysis will not be withheld just because a patient is old. There is no upper age limit. But some of our more elderly patients also suffer with other medical conditions that would make dialysis impractical, unpleasant or perhaps even harmful.

Do many people choose conservative management of their condition?

It is not uncommon to choose conservative treatment. In our unit, about one in five of the patients assessed for dialysis decide on this option.

If I choose not to have dialysis, will it be seen as committing suicide?

Sometimes, patients worry that the decision for conservative management is equivalent to suicide. This is not the case. An individual has the right to decide not to accept a medical treatment. Many religions also support this right to choose.

In some patients, dialysis may not extend the length of life and often detracts from the quality of life. A recent study in our unit has shown that dialysis does not appear to extend the life expectancy in high-risk or highly dependent patients. Indeed, there appeared to be some distinct disadvantages to receiving dialysis. Patients receiving haemodialysis were obliged to spend a large proportion of their time in hospital receiving the treatment, being treated for complications of the treatment or being transported to and fro.

When it comes to the end of life, many patients prefer to die at home, in their own surroundings, and with their families in attendance. The increasing medical involvement that accompanies dialysis appears to be a barrier to this choice.

Will I still see the renal team?

Many patients and their families are concerned that, if they decline dialysis, they will be abandoned by the renal and liaison team. This is not the case.

Regular follow-up and treatment at the clinic will continue. In addition, continued assessment will also be made to ensure that services that may be required as circumstances change, will be available.

Are there medical treatments available other than dialysis?

Yes, if you have chosen conservative management, your medical team can provide you with treatments that will help to protect your remaining kidney function, as well as treating the symptoms of renal failure. Some aspects of kidney failure are not treated with dialysis.

You can still feel well if you have some remaining kidney function and although this tends to gradually decline, there may be measures – such as lowering your blood pressure – that can slow the rate at which it declines. The multidisciplinary team will include doctors, nurses and dietitians, who will be able to provide advice about whether you need to alter your diet or fluid intake and what drugs may help.

You should also check with the medical team before taking any over-the-counter medications, or if you become unwell for other reasons. For example, diarrhoea or vomiting, which you might normally have treated yourself, may need more specialist help if you have established renal failure.

Box 1. Getting your affairs in order once you have chosen conservative management

If you choose conservative management, you may want to make sure the following is in order.

- Your will.
- A living will (which outlines your medical preferences should you be unable to speak for yourself – for instance, whether you would like to be resuscitated).
- Power of attorney, so that someone can make legal, financial, banking and business decisions on your behalf.
- An inventory, including the location of your bank, financial accounts, stock and bond holdings, real estate and business records, medical and other insurance policies, pension plans and other legal papers.
- Names, addresses and telephone numbers of your attorney, accountant, family members and other loved ones, friends and business associates who should be notified of your death or who may have information that will be helpful in handling estate affairs.
- A statement about your preference for funeral or memorial services, burial or cremation instructions and decisions about organ and tissue donation.
- Written, video- or audio-taped messages to family members and other loved ones, business associates and friends.

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Family members may find caring for their loved one at home a daunting prospect, but help and support are available

What other services will be available to me?

Close relatives may feel daunted at the prospect of having to care for their loved one at home but, through early involvement of district nurses, GPs and palliative care teams, help and support can be provided to prevent the need for admission to hospital. We can involve social workers to help

with social, housing and financial issues, and specialist nursing can sometimes be arranged. Patients and their loved ones can plan their goodbyes and finalise personal and financial matters (see Box 1, page 17). Support may be available to help with the additional costs of providing end-of-life care at home.

Palliative care teams of specialist doctors and nurses are increasingly becoming involved in helping our conservatively managed patients. Their expertise in symptom control, and access to the range of support services, can be an important additional source of help.

Some hospices admit kidney patients who have chosen conservative management. Hospice care is designed to take into account the needs and feelings of both patients and their families.

What symptoms and signs can I expect as my kidneys deteriorate?

As the kidneys deteriorate, patients may experience a wide range of symptoms that usually develop gradually over a length of time. One of the most striking is lethargy and weakness caused by anaemia. This is partly due to the lack of a hormone called erythropoietin (or EPO) and sometimes due to deficiency of vitamins and iron. EPO can be replaced by injection (into the fat under the skin) and iron can be supplemented by tablets or by intravenous injection.

Patients with advanced renal disease often note that their appetite is reduced or complain that food tastes funny due to the build up of toxins in the blood as the renal failure advances. The renal dietitian, who will assess you and help to modify your diet accordingly, can address some of these issues.

Many patients notice their skin becoming darker and dry with time. The skin can become very itchy. Sometimes the use of oil-based soap substitutes and emollients can help, and some gain relief from antihistamines. Dietary modifications can help to reduce the severity in some patients. Unfortunately, it can prove impossible to completely eradicate this symptom.

In some patients, particularly those that do not pass much urine, fluid can build up near the body's surface, causing swelling of the legs, and in the lungs, causing breathlessness. Medicines to encourage increased urine output (diuretics) can be given in high doses to help prevent fluid retention; if the sensation of breathlessness is more severe, then oxygen by mask or nasal cannula may help relieve this symptom.

How long will I live?

It is very difficult to predict how long someone will survive when they have established renal failure. It can range from a few days or weeks in those whose kidneys have completely failed, to several years in those whose kidneys still retain some useful function. It depends on several factors, including the rate of decline of kidney function, other medical conditions, general level of health and diet. You can discuss this with your doctor, who may be able to give you a rough estimation of life expectancy, but it is impossible to be very accurate.

Treatment is targeted at symptom control, and our aim is to ensure that patients retain a sense of control. In the final stages, oral medications can be withdrawn and replaced by subcutaneous injections or pump devices, as appropriate.

Death due to kidney failure is a progressive process. At the end, the patient may become drowsy, often slipping into coma before death, which is usually peaceful and free of suffering ■

Key points

- **In selected high-risk patients with other serious medical conditions, dialysis may not extend life and may, indeed, detract from quality of life.**
- **In high-risk patients, a more conservative approach to care can still provide medical, physical, psychological and practical care for both the patient and their immediate family.**
- **It is important not to confuse rationing of dialysis with rational use of dialysis.**
- **Conservative management of established kidney failure is a valid and widely acknowledged treatment option, which does not equate to suicide or euthanasia.**

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More information about conservative management of established renal failure can be found in a Kidney Research UK publication, *Choosing not to start Dialysis*, which is part of the series, *Kidney Health Information.* You can download it from the website (www.kidneyresearchuk.org – click on 'Information', then 'Factsheets'), or order it by calling the helpline on: 0845 300 1499.

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