What I tell my patients about conservative kidney management

Most major religions agree that conservative kidney management is not akin to suicide

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Kidney disease is becoming more common in the western world, especially among older people. This has led to greatly increased numbers of older patients starting dialysis. Many of these patients have other medical problems, such as heart disease and diabetes; many are also quite frail, and need help and support. Dialysis in these circumstances can be burdensome, and survival may not be greatly prolonged.

Most UK kidney units now offer patients with advanced kidney disease the option of conservative kidney management. This is where the patient chooses not to have dialysis, but continues to receive help from the multidisciplinary renal team with managing and controlling their symptoms, with social support and palliative care input where needed. The exact nature of conservative kidney management programmes will vary between kidney units. In most cases, patients will continue to attend a nephrology clinic, but will have support from specialist nurses and can be referred to palliative care and social work teams if necessary. Some units have shared care arrangements where, instead of having to come into clinic, housebound patients are seen at home by their GP and a community matron – often in close telephone contact with the nephrology and palliative care teams.

Why might I choose conservative management instead of dialysis?

Choosing a treatment is a very personal decision, and everybody is different. For some people, haemodialysis will be the right choice; for others, peritoneal dialysis will suit better. For some patients – particularly those who are dependent, or have other serious medical problems – managing symptoms as they arise may well be the best choice. There are a number of reasons for this.

- Some people with advanced kidney disease have very stable kidney function, and may never actually need dialysis. Many patients on conservative kidney management programmes die because of other medical conditions, not because of their kidney disease.
- The choice of types of dialysis is somewhat limited. Dialysis at home, either by peritoneal dialysis or by haemodialysis, is an option for some. Patients who choose this form of treatment need to be trained to perform the treatment for themselves at home. Family members can sometimes be trained to take on some of the work. There needs to be enough room space in the home to accommodate the machinery and supplies, and having access to some support within the home is often considered to be important. All of these requirements mean that home dialysis is often not feasible for many older, dependent patients with multiple medical problems.
- The most common form of dialysis treatment is centre-based haemodialysis. This involves treatment in the kidney unit for up to four hours, three times a week, which is very time-consuming. Add in the need for transport, and time spent waiting for it, and you might be away from home for eight hours or so.

Haemodialysis sessions can also be complicated by unpleasant symptoms such as muscle cramps and dizziness, and it is not uncommon to feel washed out for a number of hours after the session. Patients with other medical problems are more prone to these symptoms. Many of our older dialysis patients tell us that they can find all this quite exhausting. It can feel like your entire life and that of your family revolves around dialysis.

Taking all these things into account, your quality of life may well be better on conservative kidney management than on dialysis. Also, in some situations, survival may not be greatly prolonged by dialysis. It needs to be stressed, though, that these factors are different for each individual and that there is no magic formula to dictate what to do. For every individual, the options need to be carefully considered and discussed between the patient, family and carers, and the multidisciplinary renal team.

But wouldn't I feel better on dialysis?

The beneficial effects of dialysis depend on a number of factors – in particular, the nature and the cause of any symptoms you might have. Patients with advanced kidney disease can have many different kinds of symptoms, a lot of which can be improved by dialysis. However, some patients may continue to experience symptoms, the most common being lack of energy, tiredness, pain, poor appetite and breathlessness. As mentioned above, haemodialysis patients may also experience symptoms related to the dialysis sessions themselves, including muscle cramps, dizziness and feeling 'washed out'. In addition, if you suffer from other medical conditions, dialysis will not normally improve the associated symptoms, and those conditions are likely to continue to progress.

Of course, conservative kidney management patients also experience symptoms due to kidney disease and other medical conditions. In short, it may not be that clear whether patients on dialysis feel better than those on conservative management (where, after all, the whole aim is to treat symptoms). It does seem, however, that patients on conservative kidney management who are coming towards the end of their lives often maintain a pretty stable functional status until they are very close to the end.

What symptoms will I have?

As described above, people with advanced kidney disease can feel tired and lack energy. This may be at least partly due to anaemia, in which case treatment with iron or erythropoietin injections may be beneficial, whether patients are on dialysis or conservative kidney management. Poor appetite and nausea can be helped by anti-emetics (anti-vomiting treatment) and by dietary advice and supplements. There is a tendency to retain fluid, which might lead to leg swelling or breathlessness. This can usually be helped with diuretics (water tablets) and by limiting your salt intake.

Some people also experience itchiness and dry skin. Taking phosphate-binding tablets with meals can help with this. Moisturising creams and antihistamines may help too. Pain may occur, but usually responds to standard painkillers. Severe pain is unusual, but can also be managed.

Will my life be shortened?

It is difficult to be sure whether conservative kidney management will shorten a patient's life without knowing the precise details of that individual's clinical condition and general circumstances. A patient whose kidney function is declining rapidly, but who is otherwise relatively independent and well, is likely to survive considerably longer on dialysis than on conservative kidney management. On the other hand, a dependent patient with other serious medical problems, whose kidney function is stable or declining slowly, may survive for much longer on conservative kidney management than they would on dialysis. It is important to recognise, however, that these scenarios are at the opposite ends of the spectrum of possibility and that for most individuals, the prognosis is much less certain. Understanding the options usually comes down to harnessing the experience and clinical judgement of the clinical team, along with the concerns of the family and carers, to inform the patient's personal preferences.

Your quality of life may well be better on conservative kidney management

On average, choosing not to dialyse is probably associated with a slightly shortened life expectancy. The trade-off is relief from the burdens imposed by dialysis, and the hope of a better quality of life in the time remaining. It has been shown that, on average, older patients on dialysis live ten months longer than patients on conservative kidney management, but that they spend much of that extra time in hospital, or attending dialysis sessions and other appointments.

What support will I have?

You will continue to see the nephrologists and the renal nurses regularly in the clinic. Other members of the multidisciplinary team will also be involved as required, including dietitians, social workers and renal counsellors. Many renal teams will identify a key worker – often one of the nursing team. The key

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worker will assume an important role in co-ordinating care in both the renal setting and the community. The key worker may also be the best person to help you plan your preferences for care in the future, and to ensure that you and your family receive the support you need. This can be formalised in a care plan, which can be shared with your GP and other members of the wider team, and updated as time goes on.

Communication with your GP and primary care nursing team is vital, to ensure that you have access to the care you need in the community when you need it. Teamwork is essential, and establishing contact with hospice services and the Macmillan nursing teams may be important as time goes on, depending on your preferences.

How do I decide?

Members of the renal team will be there to discuss the treatment options with you and your family over a number of clinic visits. Many kidney units will also offer to organise for members of their team to visit you and your family at home, so that discussion can take place at a more leisurely pace and in more comfortable and familiar surroundings than the standard outpatient clinic. Most people find this very helpful in coming to an understanding of their options and in making a decision about which is right for them. Making a decision is the first stage of planning future care; this should be continued throughout future clinic visits.

What if I change my mind?

Most patients who opt for conservative kidney management see this as the option that will best preserve their quality of life for as long as possible. Having said that, the decision is not set in stone. If you decide on conservative kidney management and subsequently change your mind, it would usually be possible to change to dialysis. Sometimes, though, patients have such severe medical problems – such as severe heart failure with very low blood pressure – that dialysis may not be technically possible.

The other issue to consider in this situation is timing. If the decision to change is delayed until a patient is very ill, starting treatment becomes much more complicated and hazardous – 2 am in the A&E department is the very worst time to choose dialysis! Having time to plan will give the best assurance of the best outcome, whatever your choice.

I don't want to have dialysis, but my family say that refusing dialysis is like committing suicide – what should I do?

Your family and friends want what is best for you – and, of course, they do not want to lose you. The likelihood, though, is that they would respect your decision if they understood the facts upon which it is based. In the end, the decision is yours, but achieving a level of general understanding is important. Many people do not really have an idea of what starting dialysis will entail, and when they realise how burdensome it can be, they are usually a lot more open-minded. You may find it useful to involve the doctors, specialist nurses or other members of the renal team in discussions with your family. Many renal teams also have access to counsellors and psychologists who may be very helpful in this situation.

It should be stressed that the aim is that you have the best quality of life possible in the time available and can spend time at home with your family, doing the things that you want to do, rather than in hospital.

I'm religious – do I have a duty to have dialysis?

Conservative kidney management is not akin to suicide. Individuals have the right not to accept any treatment they feel it will not benefit them. Most of the major religions take this position. You may wish to talk with your religious advisor if you still have concerns.

Where can I find more information about conservative management?

Your local unit will be able to tell you more about which services are offered locally, and how their conservative kidney management programme is run. For general information about kidney disease, including the decision not to dialyse, the British Kidney Patient Association has lots of leaflets on its website. For more general information about palliative care, the Marie Curie website has lots of information, too ■

Declaration of interest
The authors declare that there is no conflict of interest.

Further reading
www.britishkidney-pa.co.uk
www.mariecurie.org.uk

Key points

- Dialysis can maintain life for patients with advanced kidney disease. However, for older, more dependent patients – especially those with other serious medical problems – dialysis can add to these burdens, and may not improve survival significantly.
- Some such patients choose to forego dialysis and opt for conservative kidney management instead, which focuses on the management of symptoms and the maintenance of quality of life.
- The decision to opt for conservative kidney management is based on individual circumstances and preferences.
- Most kidney units provide conservative kidney management programmes that offer multidisciplinary support for the patient and their family, in conjunction with primary care and community palliative care services.