

CHAPTER 4

CONSERVATIVE MANAGEMENT (RENAL SUPPORTIVE CARE)

Chapter 4 - Conservative management (Renal Supportive Care)

If you are thinking about having a transplant or starting dialysis, you may not need to read this chapter.

However, if you are unsure about whether dialysis or transplant are right for you, you might find the following information helpful.

What is conservative management?

It is reasonable for some patients to choose, after consultation with their kidney team, not to have dialysis. Having dialysis is onerous, and for some patients with other medical conditions it may not improve survival to any great extent. In conservative management kidney function is not replaced. This means that you do not have dialysis or a transplant. The aim of conservative management is to maintain a good quality of life by prolonging kidney function, controlling symptoms, and supporting patients, their families and carers. Good planning and communication can help avoid inappropriate hospital admissions. When you are managed conservatively, there will be a core group of professionals involved in your care. This will include kidney and renal supportive care team, your GP and district nurses. The aim is to ensure that you are cared for in a way that suits you and meets your needs.

The aim of conservative management is:

1. Preventing and treating the symptoms of chronic kidney disease.
2. Protecting and maintaining remaining kidney function.
3. Planning for the future.

"I know it was the right decision not to start dialysis. I know the treatment may extend my life by approximately one year possibly two years, but I have had this time with improved quality of life. I am so much happier as a result of the support I am now receiving."

Mr J, 84 years

"The normal process is that I will die one day but the support I have had from the renal supportive care service means that I no longer worry about it. Of course I understand that I cannot be cured of my kidney disease but I am now able to cope with my condition."

Mrs W, 79 years

"Without the renal supportive care service life would be so much more difficult for the patients and their families. I feel it is not about the treatment you receive but the way care is delivered."

Mr P, 82 years

"In my view the transfer from the normal clinic to the renal supportive care clinic was so smooth. I feel I can ask anything in this clinic. I feel so much happier – the approach of the renal supportive care team is so personal and uplifting. I feel closer to the people looking after me. My whole family knows who to contact."

Mrs P, 74 years.

Preventing and treating the symptoms of chronic kidney disease

When your kidneys are no longer working properly, you start to experience symptoms caused by the build-up of toxins in your bloodstream. Symptoms can include:

- tiredness
- itching
- pain
- breathlessness
- restless legs
- sickness

The symptoms of CKD can affect people in different ways. If symptoms do occur, they can usually be relieved by medical and/or non-medical treatments. It is important to tell the doctors and nurses looking after you if you are experiencing symptoms, so that they can be effectively treated.

Protecting and maintaining any remaining kidney function

The things that slow down the progress of kidney disease include:

- managing your blood pressure
- good blood glucose control if you have diabetes
- preventing you having too much fluid in your body

As your illness progresses we will focus more on maintaining quality of life by controlling symptoms as they arise.

Planning for the future

This means thinking about how and where you want to be cared for when you become less well and at the end of your life. This might be your own home or a hospice

Is any surgery involved?

There is no surgery involved.

Can I make an advance decision about treatment I do not want?

Yes, you can decide what treatment you do not want if, in the future, you are unable to make decisions yourself. Please ask your healthcare team for more information about doing this.

How long will I live?

This varies for each individual. There are many things that affect how long you will live, including if you have other illnesses and how well your kidneys are working. Your healthcare team will be able to discuss this with you in more detail and will explain the things that can affect this.

Can I change my mind once I have decided not to have dialysis?

Yes. We will support you in any decision you make. However, if you change your mind it might be because you are starting to feel unwell which may mean you need dialysis immediately. Starting dialysis in an emergency is not as easy as starting it in a planned way.

More information

What can I do?

- Talk to the renal supportive care nurse.
- Talk to your family and friends about your choice.
- Take time to make the decision.
- Talk to the Renal psychology service. Contact details are in the Chapter about Renal Service.