

# Dialysis or not: choosing what is best for you

## Renal Department, St George Hospital.

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For people with chronic kidney disease there is no specific pill or operation. In other words there is no cure. For some the disease will progress to a stage where treatments such as dialysis and or transplantation are recommended; for most the condition will still progress but at a slower rate, hopefully avoiding the development of end stage kidney disease.

In essence there are three options for anyone who has chronic kidney disease which progresses to a stage where they have poor kidney function and are perhaps experiencing symptoms:

- Transplantation for the healthy
- Dialysis either peritoneal or haemodialysis and
- No dialysis i.e. conservative management

Juggling medications, perhaps dietary restrictions and certainly a healthy lifestyle are all important no matter what option you choose.

Sometimes the decisions regarding what option is best for you are difficult especially for people who have little understanding of kidney treatments. Your healthcare team including your kidney doctor, nurse consultant, social worker, dietician, GP and others are available to assist you in your decision making.

Providing you with information about treatment options early in the course of kidney disease allows you the time for it all to sink in. There will be time to gain information about the dialysis options and about what it might be like if you decide not to take up dialysis.

You can decide not to take up dialysis. You have the right to refuse treatment you do not want. It is preferred that this decision is informed which means you have an understanding of the other treatments and what they entail. Making decisions is a way that patients exercise their right to be involved in their health care.

There is information your kidney doctor can use to assist you in your decision. As you can imagine your other significant diseases and your age will impact on your future health no matter whether you choose to proceed with dialysis or not.

It is a good idea to involve family, friends and carers in your decisions as it will also affect them and the healthcare team encourage that to happen. Occasionally, patients and family members have unrealistic expectations about what dialysis can achieve. Dialysis is not a 'cure' for kidney disease. Ultimately it is your decision as to what you want to do about treatment for your kidney disease.

## **What symptoms might I experience and how can they be managed?**

Everyone is an individual and they respond to kidney disease in different ways. Most patients will report an increase in tiredness and inability to do the physical activities they once could manage. You may also experience emotional changes, appetite changes, itchiness, changes in breathing and fluid accumulation.

## **Support at St George Hospital**

Some patients think that if they choose the 'no dialysis' option they will be abandoned by their kidney doctor and healthcare team. Sometimes patients have been visiting their kidney doctor regularly for a number of years and if you choose not to have dialysis you will continue with these visits. As explained, it will be necessary to monitor you closely and review your medications. In addition, some new medications may be indicated to help control some of the symptoms of kidney failure.

At St George Hospital we pride ourselves on the support we provide for people who choose not to have dialysis. Our focus has always been on the quality of life and the journey of our patients. Arising from our endeavours is a number of initiatives but the most exciting is the renal palliative care clinic.

The strong partnerships we have forged with the palliative care service at the hospital has allowed us to use the expertise of these doctors and nurses to help in kidney failure management. The service is crucial in controlling and supporting patients with symptoms and when the time comes end of life care. Your kidney doctor may refer you to this clinic to help you with your decision regarding whether or not to have dialysis or to assist in controlling your symptoms if you choose not to have dialysis. Remember you will still continue to see your kidney doctor regularly.

## **How long will I live if I do not have dialysis?**

There is no set timeline and remember everyone is different and has other medical conditions which affect the length of life in circumstances where there is no kidney failure. As your health deteriorates you may experience excessive sleepiness and weakness, a decreased appetite and emotional changes. Death from kidney failure is painless and peaceful. Many patients live many months some even past a year without having had dialysis.

## **Discussing your wishes with your loved one and preparing your personal affairs**

Many people find it difficult to talk to their loved ones about their wishes as they worry about how others may feel and react. Your renal team – doctor, nurse and social worker are available to talk to about how you might do this. It is often easier to talk to someone you trust and who makes you feel comfortable.

Although you may find it hard the best approach is to discuss your feelings openly with your loved ones. It will become easier if you can all be honest and understanding of each other's opinions and feelings. If you wish, a member of the health care team can be present to support you when you speak with your family.

When you have been informed that you have a serious form of kidney disease it is important to get your personal affairs in order. This will assist your family and ensure that your personal wishes are adhered to.

It is important to inform your general practitioner, kidney doctor and most importantly your family about your wishes.

#### Discussions around

- How and where you would like to be cared for
- Who is your person responsible
- Arrangement of a will
- Arrangement of enduring medical power of attorney
- Arrangement of enduring guardian
- Organisation of your financial records – bank accounts, insurance policies, real estate etc
- Discussion with your loved ones of the choices for funeral services

We are here to assist with supporting/making these decisions and ensure your best possible quality of life.

#### **What do I do if I have more questions?**

You should talk with a member of the healthcare team if you have more concerns. They will be happy to answer any questions regarding your treatment and care.

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