There is no cure for kidney failure other than Transplant and as the kidneys deteriorate further symptoms may now include:

Lethargy/tiredness
Drowsiness
Increased or a decreased urine output
Loss of appetite/ metallic taste in mouth

Difficulties in sleeping, restlessness.

It is important to remember that no matter what your symptoms are there is support and advice available. As your kidneys deteriorate and your symptoms progress, you may now have more involvement with members of the multidisciplinary team. The aim of this involvement is to provide the care that is needed to ensure that end of life is optimised with quality and dignity.

QUESTIONS AND ANSWERS

If I choose not to have dialysis will I die sooner?

There is evidence to show that some people live longer than patients who have chosen to have dialysis, (usually dependent on age and other co-morbidities). However some people may die sooner but retain a better quality of life following a Conservative care pathway.

Do I have to die in hospital?

Some patients choose to die in hospital others choose to die at home or in a hospice. This is a decision that can be planned with your family and the multidisciplinary team over time.

Can I change my mind?

This decision can be changed at any time. If you have questions, doubts or fears about your decision please discuss them with your renal team. The team will ask you from time to time whether you would like to make any changes to your plan.

Do I still need to come to hospital?

Some people feel that they still want to attend clinic to check their kidney function and to keep in contact with the renal team. However other patients may decide that they do not want to attend the hospital. In these cases, arrangements will be made for telephone contact with the Specialist Nurses who are able to offer advice and support as required.

Will I get pain?

Most patients do not get pain from their kidneys, however if patients experience discomfort or pain this would be relieved with pain relief.

If you have any further questions please contact Ruth or Lorraine (CKD Nurses) on the telephone numbers provided.

CONSERVATIVE MANAGEMENT

OF

CHRONIC KIDNEY DISEASE

BLJ/HRG Nov 2010

This leaflet is written for those patients who choose not to have dialysis treatment. We hope to provide a clear and honest account of the treatment available, how your kidney problem may progress in the future and what this will mean for you.

As a patient you will have been attending the hospital for 'kidney problems' for some time and have now been informed that your kidney failure has progressed to the stage where you may be required to make decisions regarding your future treatment. You may now be feeling frightened, and unsure of your future, what your kidneys failing means to you and what forms of treatment are available.

Chronic Kidney Disease is a term given to describe the progressive deterioration in how your kidneys are functioning. As the kidneys deteriorate, the waste products will build up in the body and this may result in the symptoms of kidney failure. These symptoms will be discussed later in this booklet. There are different treatments for your kidney failure all of which have both advantages and disadvantages, which your renal team will discuss with you.

At this stage in your care the renal team will have discussed with you the various options available. Having discussed these options with your family/carers, your renal consultant and nurses you may decide not to have dialysis treatment. This decision can be discussed further with your doctor and/or nurse at any time. The renal team will support your decision and provide you and your family with as much guidance and information as you need for your future care.

The aim of this leaflet is to provide you with information about what to expect if you choose not to have dialysis therapy.

Following your decision not to have dialysis treatment, what happens next?

Conservative care is a term used to describe the care and treatment received by those patients who choose not to have dialysis. Conservative care means that you will still receive treatment, still have regular outpatient's appointments and have input from the renal team.

We hope that we will be able to optimise your care, keeping you feeling well for as long as possible with no particular symptoms. This may change over time. Your renal team will have explained to you that they are going to refer you to other members of the multidisciplinary team so that future care may be planned ,and at differing times these may include:

Dietician For advice regarding healthy diet and on occasions food that you may need to avoid or restrict. Dietary supplements that can be taken if required.

Social Worker For support for you and your family. Financial advice may also be sought as your circumstances change.

Psychologist For advice on coping strategies, counselling and stress management for yourself and your family/carers if required.

Pharmacist For advice about your medications to help optimise treatment.

General Practitioner Your G.P. will be able to provide you with medical support in the community, and visit you at home if necessary.

District Nurse Who will be available if care is needed in the home and for assistance with medication if required.

In later stages we may involve Special Palliative Care Teams for assistance with symptom management and support for both you and your family.

This is not a complete list of services which can be provided, or a full description of the roles that they do, to ensure that your care and management is to a high standard.

The renal team will also be available to provide support, care and advice throughout the various stages of your treatment.

At some point in the future, symptoms of your kidney failure may become apparent. This may mean starting new, or adjustments to your medication and diet.

Symptoms you may feel:

Nausea and/or Vomiting. There are numerous medications that can be used to help control this and may be administered in various ways to provide maximum relief.

Tiredness This may be due to anaemia, which you may already be on a form of treatment for this. If not treatment can be commenced if required.

Itchiness This can usually be controlled with diet and medication. Creams may help.

Swollen ankles/legs This can normally be controlled with medication.

Headaches Checking that your blood pressure is controlled well may prevent this side effect, also can be helped with simple pain relief.