

# **Patient Information**

# What happens when you are referred to the Advanced Kidney Care Clinic

Renal Department



# Why am I attending the Advanced Kidney Care (AKC) Clinic?

You have been referred to the Advanced Kidney Care (AKC) Clinic because your kidneys are not working effectively. This means they are not doing their usual jobs, such as:

- removing excess water and waste products from your blood
- keeping your bones strong
- regulating your blood pressure
- helping you make red blood cells

This change may have happened suddenly or over a period of time. This is usually detected from blood and urine tests even before you have any symptoms.

# What is the Advanced Kidney Care Clinic?

There are different stages of chronic kidney disease (CKD).

The Advanced Kidney Care Clinic looks after patients at CKD stages 4-5; those whose kidneys are working at less than 30% of normal.

At this clinic we hope to slow down and stabilise the decline, but most people with CKD may eventually need renal replacement therapy (RRT).

This means some people will need dialysis or a kidney transplant to do the work of their failing kidneys.

# The aims of the Advanced Kidney Care Clinic

- To ensure you are receiving the most appropriate treatment to slow the decline and to prolong your kidney function for as long as possible
- To provide education and advice that enables you to make health and lifestyle changes if required
- To manage the side effects of CKD and to improve any symptoms
- To provide education and advice that enables you to make an informed decision about RRT options, if needed
- To ensure timely and appropriate referral for all interventions in preparation for RRT
- To support and provide the appropriate care to those who do not want RRT

# Who will I see at the Advanced Kidney Care Clinic?

#### **Specialist Kidney Doctors**

You will be reviewed by a consultant nephrologist (kidney specialist) and specialist renal doctors who will manage your renal symptoms and medications. If your kidney function stabilises or improves you may be referred back to your GP or a general nephrology clinic.

#### **Advanced Kidney Care Clinical Nurse Specialist (AKC CNS)**

The AKC CNS works alongside the medical and multidisciplinary team (MDT) in managing areas of your treatment by ensuring good renal health management. They provide information and support so that you can make informed decisions regarding your ongoing care.

The AKC CNS, along with the Renal Social Worker Team (RSWT) will support and prepare individuals and their family and/or carers through this decision making process.

#### Renal Social Work and Renal Psychological Services

These teams offer a wide range of support and input from various professionals. The aim is to ensure that all elements of your care are attended to, including your social and psychological needs. The teams consist of social workers, a benefits advisor and counsellors.

#### **Renal Dietitian**

Good nutrition is important at all stages of kidney disease, including delaying the progression of kidney disease. The dietitian provides specialist renal dietary advice to help reduce the impact CKD has on your general health.

#### **Renal Pharmacist**

If needed, you can arrange to see the renal pharmacist to discuss your medication therapy and provide additional information on medication you are taking. They also prescribe your erythropoiesis stimulating agents (ESA) therapy.

### Virtual clinic appointments

Since the COVID-19 pandemic we have adapted our service and are now able to hold clinic appointments either over the phone or via a video link in 'virtual clinics'. This means that we can offer you a service from the convenience of your own home

### What should I bring with me to my clinic appointment?

Please have ready with you:

- a list of your current medications
- a record of your home blood pressure readings (if you have a blood pressure monitor)
- an update on your hepatitis vaccinations, if applicable

# How can I prolong my kidney function?

- Take your medications as prescribed
- Avoid adding salt and having salty foods in your diet
- Stop smoking
- Lose excess weight
- Keep as active as possible
- Optimise blood pressure control
- If you have diabetes, aim for good blood sugar control
- Attend your renal clinic appointments and follow all the medical advice given

# What will happen if my kidneys fail?

As your kidney function declines, the waste materials and extra fluid in your body can make you feel ill. At the appropriate time, the AKC CNS and a member of the RSW team will arrange a joint discussion around renal replacement therapy options with you and your family.

# What are the possible renal replacement therapy options?

- Kidney transplant where you have a new kidney from a donor, either living or deceased. Not everyone can have a kidney transplant.
- Dialysis where treatment filters your blood, taking on some of the work of your kidneys.
- Conservative management where your symptoms are managed by medicines. This supportive care pathway does not involve invasive treatment.

### What if I do not want dialysis?

If you decide not to have dialysis (opt for a non-dialysis option), you will still be seen by the renal team and your kidney disease will be managed between the renal MDT and your GP.

# Adjusting to life with kidney failure

#### Keep a positive attitude

This allows you to see all the possibilities when they may not be obvious to you.

#### Find out all you can at the Advanced Kidney Care Clinic

Write down specific questions you want answers for. Have a relative or friend with you.

#### Build up a good support system

Inform the people that are important to you about your kidney condition so they can support you if you are worried.

#### Take responsibility

Take an active role in your own wellbeing, both physically and emotionally. The renal team and your family/carer can help you but making the choice is up to you.

#### Shared decision making

Work with the renal team to decide which treatment option is best for you.

# **Advanced Kidney Care Nurses**

We are available to speak to you Monday to Friday, between the hours of 9am-1pm.

If you call after 1pm, please leave a message on the answerphone and your call will be returned the following working day.

Telephone: 01438 285255

Email: advancedkidneycare.enh-tr@nhs.net

#### Anaemia queries

For all queries relating to anaemia (Iron and ESA)

Telephone: 01438 286368

Email: renalanaemia.enh-tr@nhs.net

# Glossary

Below are some of the abbreviations used in the renal department and in this leaflet:

AKC - Advanced Kidney Care

CKD - Chronic Kidney Disease

CNS - Clinical Nurse Specialist

ESA - Erythropoiesis Stimulating Agents

MDT - Multidisciplinary Team

RRT - Renal Replacement Therapy

RSW - Renal Social Worker

RPS - Renal Psychological Service

# **Outpatient Clinic Telephone Numbers**

Lister Hospital	01438 285533
St Albans	01727 897407
Chiltern Kidney Centre	01438 288869
Bedford	01438 286752
Harlow	01279 278200

#### **Other Useful Numbers**

Ward 6B, Nephrology (Renal) Ward, Lister Hospital	01438 285063
RITA (Renal Intervention Treatment Area)	01438 284775
Renal Social Workers and Psychologists	01438 284957
Renal Dietician Team	01438 285533
Home Therapies	01438 284100
Vascular Access CNS	01438 284624
Kidney Transplant CNS	01438 285466
Patient Transport	01603 481208

#### **Further Information**

Kidney Patient Guide www.kidneypatientguide.org.uk

Kidney Care UK www.kidneycareuk.org

Baxter Health Care mykidneyjourney.baxterhealthcare.co.uk

NHS Choices www.nhs.uk

UK Kidney Association www.renal.org

National Kidney Federation www.kidney.org.uk

www.enherts-tr.nhs.uk

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