

YOUR KIDNEYS, YOUR HEALTH

**A guide to living with
Kidney Disease**

Introduction

When kidneys fail, it is a major life changing event. The pattern of daily life has to alter substantially. It is natural for patients facing kidney failure to want to seek information in order to help them learn about their condition and how best to manage and come to terms with the changes involved. Questions about the disease may arrive for individuals at different stages throughout the journey of kidney failure.

We have, therefore, developed this guide to help and advise our patients about the choices and treatments available when they need to consider renal replacement therapy.

Within this guide we have written sections on Healthy Living Advice and Living Life to the Full as we feel life on dialysis should not be all consuming but part of the treatment for your condition. Our motto is to ensure "Patients Dialyse to Live, not Live to Dialyse".

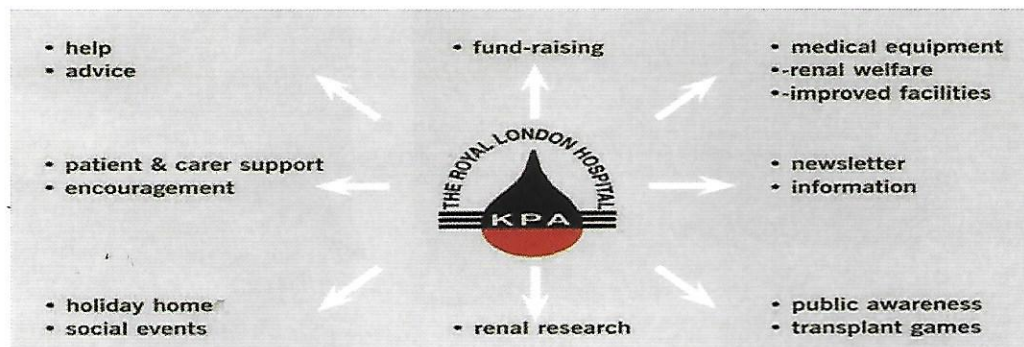
People with kidney failure may undergo a program of dialysis, diet and fluid restrictions, drug treatment and social and psychological support. Even transplant patients need regular monitoring of their condition. Treatment is lifelong and can be complex.

Life with kidney failure should be a partnership between the patient and the medical support in their kidney unit (renal centre). Our kidney unit can offer a wide variety of treatment and support but we do ask that our patients should comply with the treatments offered and modify their lifestyle as appropriate to ensure that your treatment is as effective as possible. It is unreasonable to expect our patients to do this, however, without our help in understanding your condition and the treatments on offer.

Our staff in the Kidney unit will try to help with this as much as possible but this guide is also a resource for you and your family to better understand kidney failure and its treatment. It should assist patients to take up the challenge of kidney failure and use the treatments on offer to maximum advantage, thereby enabling them to live longer, healthier lives.

We would like to thank the Royal London Hospital Kidney Patients' Association who have help support and finance this patient information guide.

The Royal London Kidney Patients' Association (RLHKPA) is a self-help group of renal patients, their families and friends. Working closely with the Renal Team at Barts Health, the Charity helps all renal patients of the Trust. The below are areas the group can help.



The Renal Unit:

Barts Health Renal Centre is one of the largest and most prestigious treatment units for nephrology, dialysis and transplantation in the UK, facilitating better treatment and survival rates for patients. We provide care for people with all forms of kidney disease in North East London, parts of Essex and the surrounding areas.

Our Renal service is based at the following hospitals:

The Royal London Hospital, Whitechapel

Whipps Cross University Hospital, Leytonstone

Newham University Hospital, Gateway Centre, Plaistow

Queens Hospital, Romford

King Georges Hospital, Ilford

We offer treatment to patients at all stages of the kidney disease pathway. This ranges from diagnosis of early kidney disease through to caring for patients with all forms of advanced kidney disease, including dialysis, transplantation and end of life care. The majority of the renal services are based in the Renal Centre, 9th Floor of the new hospital at the Royal London site. A list of the services provided is below.

Barts Health Renal Unit offers:

- Inpatient services accommodating elective and non-elective medical and surgical activity – comprising of 62 beds (50 Renal beds and 12 Urology beds)
- Renal & Urology Outpatient services – 27 Consultation Rooms facilitating both Renal & Urology Clinics Monday – Friday including evening clinics
- Renal & Urology Assessment unit – (See below for further information on the services available in this area)
- Haemodialysis service
- Peritoneal dialysis service – Covering both in-patient and out-patient management
- Transplantation surgery (Live Related and Cadaveric transplantation)

We treat patients with kidney disease in the following out-patient clinics:

- Nephrology – for patients with mild to moderate kidney disease requiring ongoing investigations and monitoring. This is covered in Chapter 1
- Pre-dialysis clinics – ongoing care for patients approaching end stage kidney failure who require information, education and clinical follow up with regard to renal replacement therapies. This is covered in Chapter 1
- Transplantation. This is covered in Chapter 3
- Dialysis- Haemo and peritoneal dialysis clinics. This is covered in Chapter 2
- Renal Supportive Care – providing care and treatment for patients who decide to opt for conservative care. This is covered in Chapter 4
- Anaemia - treatment of chronic anaemia including iron and erythropoietin therapy. This is covered throughout the guide.

Clinical Services:
In-patient services

The inpatient renal wards provide care for patients needing to be treated in hospital for a wide variety of renal diseases and disorders.

We offer 24-hour provision of nursing and medical care for patients:

- who are newly diagnosed with kidney disease and facing the prospect of haemodialysis or peritoneal dialysis for the first time
- who have chronic kidney disease
- who require and receive kidney transplantation
- Live Donor follow-up clinic

Both physical and psychological care is facilitated and organised within a team of ward nurses, nurse specialists, physicians, surgeons, therapists, counsellors and transplant coordinators. We recognise this patient population as unique and aim to meet all patient needs using evidence based, safe and empathetic care

Contact:

- Renal & Urology Ward 9E: 020 3594 2612 / 2619 / 2622 / 2614
- Renal Ward 9F: 020 3594 2636 / 2642 / 2643 / 2638

Haemodialysis

Please see chapter 2 to read about how haemodialysis works

We have been providing haemodialysis for patients in North East London with 'end stage kidney disease' for over 40 years. We have over 940 patients undergoing haemodialysis across all our units.

The haemodialysis unit is largely based at The Royal London Hospital but we also provide haemodialysis at the following offsite locations:

- Whipps Cross Hospital, Leytonstone
- Newham University Hospital, Gateway Centre, Plaistow
- Queens hospital, Romford
- King Georges Hospital, Ilford

Contact Numbers:

- Royal London Hospital: Reception: 020 3594 1656
Chronic HD: Staff Base A: 020 3594 0582
Staff Base B: 020 3594 0589
Staff Base C: 020 3594 0593
- Newham Dialysis Unit: 020 7055 5578/82

- Queens Dialysis Unit: 01708 435 232
- Whipps Cross Dialysis Unit: 020 8928 8888
- Patience Ward (Whipps Cross): 020 8535 6484
- Lister Ward (Whipps Cross): 020 8535 6486



Some of the Haemodialysis nursing staff you may meet when you start treatment.

Peritoneal Dialysis (PD)

Please see Chapter 2 for details as to how PD works.

Our services include:

- PD training is performed at various sites:
 - in the unit at the Royal London,
 - at the Baxter Education Centre (BEC) in Kew Gardens,
 - in the community (as needed).

We provide ongoing education for PD patients and pre-dialysis patients.

- Regular follow-ups in doctors and nurse led clinics to continuously assess and monitor our patients' treatment.
- Provision of PD care for inpatients and support for ward staff caring for inpatients. This care extends to outlying hospitals such as Barts and London Chest hospital.
- Provision of care for patients during home visits as well as in three local outreach clinics (Whipps Cross University Hospital, Newham University Hospital and Queens Hospital).
- Assisted Automated Peritoneal Dialysis (machine overnight) programme with Baxter.
- Dialysis equipment delivered to holiday destinations almost all over the world.

Location:

Our Unit is located at the Renal and Urology Outpatient, 9th Floor, North Tower of the Royal London Hospital.

Contact:

Telephone: 020 3594 1744 (Mon-Fri, 8am to 5pm)

Bleep: 1471 (via switchboard) (Mon-Fri, 5pm to 8pm, weekend and bank holidays 8am-7pm)

Out-of-hours: Renal Ward 9E: 020 3594 2612 and

Renal Ward 9F: 020 3594 2636

Out-patient Services**Kidney Transplant Service**

Our renal transplantation service has been performing life-changing kidney transplants since the late 1960's. We currently perform approximately 120 kidney transplants a year. Our transplant team includes physicians, surgeons, pharmacists, dieticians, clinical nurse specialists and live donor co-ordinators.

Transplant assessment clinic

The transplant operation and subsequent treatment can both be quite tough. It is vital that we ensure our patients are fit and well enough to withstand the whole process. To assess your fitness for transplantation, you will be seen in a pre-transplant assessment clinic. Before this happens, we will send you educational material (DVD, books etc) so that you are well informed about the risk and benefits of transplantation. Each patient will then be seen by our clinical nurse specialist and a consultant nephrologist. You may then undergo further investigations before being seen by our transplant surgeons and judged to be suitable for kidney transplantation. We work closely with a team of other specialists to ensure rapid and thorough assessment of our patients when needed.

Transplant waiting list

Once you are on our renal transplant list, you will be periodically called for review to ensure you are still in good health and able to go forward should a potential kidney donor become available. Please note, there are more patients on the waiting list than potential donors, so some patients may have to wait many years before being transplanted.

Living donor transplantation

We have an expanding and successful living donor kidney transplant program. The donors are usually family members, partners or even friends. We encourage this form of kidney donation as living donor kidneys in general, provide the best long term outcomes. We have a team of living donor coordinators who provide specialised confidential care for all our kidney donors before and after kidney donation. We offer a complex transplant service as well, performing antibody and blood group incompatible transplants from live donors and regularly contribute to the national organ sharing scheme.

Post-transplant care

Following a kidney transplant you will be monitored very closely, coming to a transplant follow up clinic, three times a week to start with. Once kidney function has stabilised, you will be reviewed every three months by the team of doctors, nurses, pharmacists and dieticians. You will have direct access to the transplant clinic team during the working day if you have any concerns or are experiencing problems.

Contact:

Reception: 0203 594 1651 / 0203 594 1653

Renal Transplant Nursing Team: 0203 594 0144 / 1749 / 1753 / 1754

Living Donor Nursing Team: 0203 594 1751 / 1752



Some of our transplant nursing team that you may meet when you come to clinic

Renal Assessment Unit

The Renal & Urology Assessment Unit opened in 2012 at The Royal London Hospital. The unit accepts renal patients who are acutely unwell. We aim to treat patients in order to prevent admission to our in-patient facilities. All admissions / referrals are discussed and need to be accepted by the renal or urology registrar before admission to the unit.

Opening hours: Mon-Fri, 8am-8pm. The last admission is accepted at 6.30pm
Contact: 020 3594 1727

Specialist teams / services

Anaemia Service

The Anaemia Service provides:

- A nurse-led clinic (nephrology patients)
- Access to expert advice (for patients, relatives, and hospital and community staff)
- Patient Education and training in the administration of medications
- Administration of intravenous iron
- Provision and administration of Erythropoietin Stimulating Agents
- Monitoring and management of patients

Contact:

Direct Line: 020 3594 1701

Clinical Nurse Specialists: 020 3594 7102

Anaemia Co-ordinator: 020 3594 7103

Renal Supportive Care Service

Renal Supportive Care is a nurse-led service that aims to support all patients who:

- opt not to dialyse
- are considering withdrawal from dialysis
- have terminal illness and are under the care of the renal team

We develop cross-boundary working relationships with the community team, as well as other specialities involved in patient care, the contact details of which are recorded in the patient passport.

The service is involved in developing the renal pathway of Coordinate My Care - in conjunction with The Royal Marsden Hospital and various Stakeholders (representing patients, carers, hospices, GPs and other community and hospital staff as well as the London Ambulance Service).

Coordinate My Care empowers patients to make choices regarding their end-of-life care. It helps our services care for patients in the community and decreases unnecessary hospital admissions. This project had been made possible through the generous funding from NHS Kidney Care. We also provide support to families and carers after the patient's death.

Contact: Clinical Nurse Specialists 020 3594 1732 or 0792 059 5266.

Pre-dialysis Service

The aims of the pre-dialysis service include:

- Delaying the progression of advanced kidney disease and long-term complications - by close monitoring of blood pressure, glycaemic control, anaemia and mineral bone disease and lifestyle changes including weight management.
- Ensuring patients are adequately prepared for renal replacement therapy and conservative management. This includes education about the disease process, treatment options and timely vascular and peritoneal access surgery.
- Providing physical, psychological and social assessment of patients with the support and involvement of their families and carers.
- Assessing the home environment for suitability for home-based treatment.
- Ensuring patients' smooth access to appropriate care pathways, including conservative management in as seamless a way as possible.
- Providing liaison between different team members including nephrologists, specialist nurses, dieticians, social workers and counsellors.

Contact: 020 3594 1728



Some of the CNS Team that you may meet when you come to clinics.

Renal Dietetic Service

Diet and Kidney Disease

Diet therapy is an important part of managing kidney disease (i.e. pre-dialysis, dialysis, transplant and supportive care). At Barts Health Renal Centre we have a team of dieticians dedicated to working with people with kidney disease. We can advise you on the best food choices and explain the relationship between diet and the progression of your kidney disease and its treatments.

We will provide practical advice taking into account religious and cultural preferences and any other conditions requiring a special diet, such as diabetes. We understand that changing the way you eat can be difficult. It is our aim to ensure that you have all the support and help you need.

We provide nutrition support for those losing weight or struggling to eat. We also carry out nutritional assessments to identify who is at risk of malnutrition or already malnourished.

We provide dietary advice and oral nutritional drinks for outpatients. For inpatients, we can provide tube feeding (directly into the stomach) and parenteral nutrition (feeding directly into the blood). We monitor the need for nutrition support with regular follow-ups.

If you are an inpatient at one of our hospitals, you can expect to be weighed and your nutrition risk monitored on a weekly basis by the nurses. If you are at risk of malnutrition, you will be referred to the dietician covering the ward.

More details are provided later in Chapter 6.

Contact the dietician on: 020 3594 1101

Vascular Access Clinic

One of the most important steps which must be taken before starting regular haemodialysis sessions is preparing for vascular access – this is the access point on your body where blood will be removed, cleaned and returned to the body during the dialysis sessions. We can provide temporary access for your initial dialysis sessions, but establishing long-term access allows for easier and more efficient removal and replacement of your blood with fewer complications.

At Barts Health Renal Centre, we provide a one-stop vascular access clinic prior to surgery. At this clinic, you will meet our nurse specialist, surgeon and anaesthetist, and you will have a range of tests that are required before the operation. These may include:

- an ultrasound scan on your forearm
- a heart ultrasound called an ECHO.
- a chest x-ray

If the team feels you are fit for surgery, a date for the operation will be discussed and booked. This will usually be as a 'day-case' which means you will not have to stay in hospital. This clinic is an opportunity for you to ask questions about your operation. Our team will be happy to answer any queries that you may have.

Diabetic nephropathy service

Long-standing diabetes (over 10 years) may cause changes in small blood vessels that can lead to damage of the kidneys. Subtle damage to the kidneys can start within a year or so of Type 1 diabetes being diagnosed and kidney damage can be present at the diagnosis of Type 2 diabetes. Nephropathy is the medical term for the type of kidney disease that occurs in patients with diabetes.

There is a high prevalence of diabetes in the north east Thames region. As a result we have established a clinic for patients with diabetes and kidney disease. This is managed by a team of kidney and diabetic consultants and specialist nurses.

Renal Pharmacy Service

As a service we have a group of specialist pharmacists caring for your drug management. As a kidney patient, you will be prescribed a range of medicines to treat the cause of your kidney failure, control symptoms and prevent complications. If taken incorrectly, these medicines may not work as effectively and may cause harm. The renal unit has a team of pharmacists available to help you with your medicines. We can provide you with information on:

- How to take your medication.
- Possible side effects.
- Interactions with other medicines and herbal remedies.
- Medication cards to help you remember when to take your medicines.

Contact: 020 3246 0134 (Mon-Fri, 9am-5pm)