



an information guide for people
with long-term illnesses

Your health, Your way ... CKD and renal failure

This booklet is aimed at people with chronic kidney disease and renal failure – long-term conditions that you may have to live with for the rest of your life.

Even though your condition can't be cured, with proper treatment it can be managed and controlled so that it doesn't dominate your life. There is plenty that can be done to control it and improve your quality of life.

Living with a long-term condition can sometimes be difficult to manage day to day. So it's important you get the right information and the right help at the right time.

If you understand your condition and its treatment, you'll feel more confident. You'll be able to take better care of yourself and be better equipped to make informed choices and decisions about your care.

So it's important to have good, reliable information about the local services available to you. Wrong or misleading information can do more harm than good. It can confuse and scare you, raise false hopes and even damage your health further.

This booklet is aimed to help you, the people around you, including family and friends, in these difficult times. It will guide you in the right direction - show you where you can get local help, support, services and information. It won't give you the answers to all your questions, but it will show you where and how to get those answers.

It is designed to point you in the right direction to find out more about your condition, your treatment, how to live with it and manage it, how to get involved with local support groups if you want to; who to turn to when you need help and support, and who to talk to if you want to discuss things with people who know what you are going through.

Your condition ...

What is ... CKD and renal failure?

Also known as chronic kidney failure, CKD is a long-lasting and irreversible condition caused by damage to the kidneys. CKD includes conditions that damage your kidneys and decrease their ability to keep you healthy.

CKD can be a serious condition because our kidneys carry out several important functions within the body, such as filtering waste products from the blood and regulating blood flow. The most common cause of chronic kidney disease is damage caused by other chronic (long-lasting) conditions, such as diabetes and high blood pressure.

It's more common in people over the age of 75. Having CKD can mean different things to different people. For some the disease can be progressive, but for many others the condition can remain stable and may have very little affect on their health.

If you've been told you have CKD, you will have lots of questions to ask. Many people who have been diagnosed with CKD automatically think they will need dialysis. Don't panic. It doesn't necessarily mean that dialysis is on the horizon. Remember that each case of chronic kidney disease is unique to each patient. The aim is to slow down kidney damage and prevent other complications

Your treatment

Treatment for most cases of CKD is done by GPs. This is because most cases are mild to moderate and do not require any specialist treatment. Your GP may refer you to a specialist if you have problems or symptoms that require specialist investigation.

The kidney unit at the **Leicester General Hospital** is one of the largest in the country and provides a wide range of services for patients with acute and chronic kidney problems, including transplants and dialysis, and has a major research programme.

The unit works in partnership with seven satellite units across the region, including a unit at Loughborough Community Hospital. There is also a home care team of nurses which provides care to patients in the community who are on or about to start dialysis treatment.

People with kidney disease are more likely to have heart attacks and strokes so it is important to prevent these. This includes lowering blood pressure, lowering cholesterol, taking aspirin and not smoking. It is also important to avoid certain drugs that can damage the kidneys and you should always tell your pharmacist about your kidney problem if you are buying medication over the counter. Certain medicines can affect the kidneys which can make CKD worse.

You should talk to your GP before using certain complementary therapies, such as Chinese medicines (and some medicines that can be bought without a prescription, such as ibuprofen) unless they are approved by a doctor who knows about your kidney problem. They can sometimes worsen kidney function in people with damaged kidneys.

Many people with kidney disease will require medicines to control hypertension (high blood pressure). You may also be asked to restrict how much you drink each day ie. tea, coffee, water.

Where can I find out more?

There are several web sites where you can find out more about kidney problems.

- **Kidney Research UK** is the leading UK charity funding research that focuses on the prevention, treatment and management of kidney disease. The charity also dedicates its work to improving patient care and raising awareness of kidney disease. Their website is www.kidneyresearch.org
- **British Kidney Patients Association** - information and support for kidney patients and their families at www.britishkidney-pa.co.uk
- **East Midlands Renal Network** - a comprehensive resource of information, advice and education about kidney problems for patients, healthcare professionals at www.eastmidlandsrenalnetwork.org.uk or www.EMRN.org.uk
- View the **Kidney Disorders Links** – give web links to useful organisations
- **National Kidney Federation** at www.kidney.org.uk or www.lkpa.org.uk the national charity run by kidney patients for kidney patients and their families with the aim of promoting both the best renal medical practice and treatment, and the health of persons suffering from kidney conditions.
- **Renal PatientView** – www.renalpatientview.org is an NHS online scheme which makes it much easier for kidney patients to get test results and other information.

- **Leicestershire Kidney Patients Association** - information by patients for patients. The Leicester Kidney Patients Association (LKPA run by volunteers giving support to renal patients and their families across Leicestershire, Lincolnshire, Northamptonshire and parts of Cambridgeshire especially those newly diagnosed. Contact Details: Chairman: Gordon Chandler
g.s.chandler@ntlworld.com; Treasurer: Carla Smith
carlamsmith2002@yahoo.co.uk or **www.lkpa.org.uk**
- **www.kidneypatientguide.org.uk** This website provides information for renal patients, partners and families, health care professionals and anyone else who is interested in kidney disease. It includes information not only on physical aspects of kidney failure - how the kidneys function, what happens when they don't, and the treatments available - but also on wider issues such as emotional, social and financial implications.
- **The British Renal Society** at **www.britishrenal.org**, information and support for kidney patients.
- **Kidney Patient Guide**, an information site for kidney patients and their families at **www.kidneypatientguide.org.uk**
- **The PKD Charity**, the charity in the UK dedicated to the concerns of people affected by polycystic kidney disease, range of inherited, incurable renal conditions, at **www.pkdcharity.org.uk**
- **The Renal Association** is the professional association of nephrologists (renal physicians) and renal scientists in the UK at **www.renal.org**.

Living with your condition

You will need to look after your health carefully for life. This may seem daunting but your health team will offer support and advice about all aspects of your treatment and they will help you produce a personal care plan which will help you manage your condition and your life.

The University Hospitals of Leicester NHS Trust kidney department produces a comprehensive '**Personal Kidney Handbook**' which is full of advice, help, support, and handy tips. Copies of this are available from your renal care team.

It is important that you get a copy of this booklet.

The team looking after you will be able to advise you about what you need to do to ensure that you remain healthy and reduce your risk of developing further problems. They may also refer you to other specialists, such as a dietitian, for further advice and support. Eating healthily and taking regular exercise are crucial to helping manage your condition.

A healthy lifestyle can help reduce the risk factors that contribute to kidney problems. You will be encouraged to create your own **personal care plan**, to help you take control of your condition, so that it does not control you.

A new booklet, called '**My Kidney Care Plan**' is now available from your renal care team to help with your self-management.

There are some important lifestyle tips that will help to slow down your condition and prevent more problems.

- Eat a healthy diet, and follow the recommended special diet if you have one. Your health team can help you.
- Take regular exercise.

- Be sure to have your blood pressure checked regularly and to take treatment that is prescribed for it.
- Don't smoke.
- You should continue going for regular blood tests. These will be organised by your GP.
- If you're buying tablets over-the-counter (particularly anti-inflammatory drugs), you should tell the pharmacist that you have chronic kidney disease.
- Listen to your health team and follow their advice.
- Cut back if you drink a lot of alcohol.

Most people with CKD feel perfectly well, but if symptoms or the effects can develop, become severe or worse. The symptoms at first tend to be vague and non-specific such as feeling tired, having less energy than usual, and just not feeling well. If you have any of the following, you MUST tell your health team:

- difficulty thinking clearly
- a poor appetite
- weight loss
- dry, itchy skin
- muscle cramps
- fluid retention which causes swollen feet and ankles
- puffiness around the eyes
- need to pass urine more often than usual
- being pale due to anaemia
- feeling sick

CKD means you will have to make some immediate changes to your lifestyle. Your body has changed, and your life may have to change as well to slow down the condition.

YOUR care plan

If the doctor has just told you that you have a long-term condition, it can be both daunting and frightening.

But you are not on your own. As well as the people look after you, there are charities, support groups, and even internet blogs and meetings where you can talk to people in the same situation as you.

They are there to give you support, help and treatment. However you are in control and you can make choices and decisions that effect your condition and it's important that you develop your own personal care plan to help you manage it. Your health team will help you with this, but there are certain things you might want to do as well.

Your feelings: Most people feel overwhelmed when they are told that they have a chronic condition. People experience many different emotions, which can cause confusion and frequent mood swings. These emotions are part of the process that many people go through in dealing with their illness.

You may find it helpful to talk to your GP, a counsellor or a member of your hospital medical team, who can help you.

Lifestyle: Changing your lifestyle can help manage and control your condition. Local help is available to support you:-

Giving up smoking: Both NHS Leicester city and NHS Leicestershire County and Rutland have dedicated teams to help you give up smoking through one-to-one advice, clinics, personal advice and nicotine patches and replacements. The City **STOP!** Team can be contacted on **0116 295 4141**, and the County and Rutland team on **0845 045 2828**.

Healthy Weight, Healthy Life: maintaining a healthy weight can have a major impact on your health. Being overweight can increase your risk of raised blood pressure, diabetes and heart disease while

being significantly underweight can impact on your immune system.

The **Leicestershire Nutrition and Dietetic service** has a team of dietitians who work in a variety of clinical specialties and can help you make informed choices about the food you eat. You can access general healthy eating advice and condition specific advice via their website at **www.lnds.nhs.uk**. If appropriate your GP or practice nurse can refer you to a dietician working within your local area.

Keeping Active: Regular physical activity can help and also reduces the risk of other serious conditions, such as heart disease and stroke. Leicester, Leicestershire and Rutland has a wide range of activities available such as gentle aerobics, cycling, salsa, walking and yoga. Every level of fitness is catered for, with help and advice readily available. Each district or borough has its own physical co-ordinator who provides advice on what's available in your area. Whether you are new exerciser; returning after a long time off; or a regular exerciser, all different abilities are catered for.

For more details, go to the Leicester-Shire and Rutland Sport website, **www.lrsport.org.uk** or telephone your local co-ordinator on:

Hinckley and Bosworth **tel: 01455 255875**

North West Leicestershire **tel: 01530 454830**

Charnwood **tel: 01509 634836**

Melton **tel: 01664 502389**

Harborough **tel: 01858 821284**

Blaby **tel: 0116 272 7704**

Oadby and Wigston **tel: 0116 257 2672**

Rutland **tel: 01572 720936**

Leicester **tel: 0116 252 7350**

Fit and Active Buddies (FAB) Project – personal trainers and cut price gym sessions to help people lose weight in Braunstone, Beaumont Leys, New Parks and Belgrave. **tel: 0778 538 5911**

Walking: www.leicester.gov.uk/walking

City Sport: www.leicester.gov.uk/sports for a variety of sport and leisure activities to suit all.

Talking to others: Meeting and talking with other people who are, or have been, in a similar situation can be both reassuring and helpful. Details of local and national support and help groups can be found on the websites detailed in this directory.

Support groups are also listed on the Leicestershire **'Infolinx'** website, a community information website run by the nine county and local councils, detailing more than 5,000 clubs, societies, organisations and self help groups based in the region. It can be reached at infolinx.leics.gov.uk

Getting the most from your medicines

Around half of patients with a long-term condition do not take their medicines as prescribed. However, for patients to take real control of their conditions, they need fast and convenient access to medicines, involvement in decisions about those medicines, advice about how to take them and information on any side effects which they may suffer.

Pharmacists have an increasing role as a source of advice for patients and their carers. There are more than 200 pharmacists throughout Leicester city, Leicestershire and Rutland who are available to help with advice and information.

Refer to the NHS Choices website at www.nhs.uk, or talk to **NHS Direct** on **0845 46 47** for details of your nearest pharmacist.

Need help or advice?

The **Patient Advice and Liaison Service (PALS)** is a free, confidential and individual service where you or your carers can be advised about the NHS, or voice your concerns about either your own or a relative's treatment. It aims to help solve any problems, concerns or questions you have when using health services in the area - a customer care service for your local NHS. PALS:

- Provides advice and support to patients, their families and carers
- Provides information on NHS services and local support groups
- Listens to your concerns, suggestions, queries or compliments
- Gives advice on how to make a complaint
- Helps sort out health concerns on your behalf
- Provides information on how you can get more involved in developing NHS services

You can contact a member of the PALS team in person, by telephone, email or letter. Patients and members of the public can meet PALS staff by arrangement.

NHS Leicester City PALS tel: 0116 295 7011 (Monday to Friday, 9am to 5pm. Outside hours please leave a message and PALS will call you). **email: pals@leicestercity.nhs.uk**

NHS Leicestershire County and Rutland PALS tel: 01455 441971
or **01509 564444**. **email: pals@lcr.nhs.uk**

University Hospitals of Leicester PALS tel: 0116 258 3100.
email: pals@uhl-tr.nhs.uk

Leicestershire Partnership NHS Trust PALS tel: 0116 225 6647.
email: pals@leicspart.nhs.uk

Other organisations that could help:

LEEAP (Leicestershire Ethnic Elderly Advocacy Project) 30 Chandos Street, Leicester **tel: 0116 275 5515**

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For city services and support groups: visit www.leicester.gov.uk/socialcare or www.leicester.gov.uk/health

The right equipment and social care

You might need special equipment to help you live at home, for example stair rails, jar openers, stair lifts, bath rails or even tap turners. If you are experiencing some form of disability as a result of your condition or its treatment, you may be entitled to help. If you are a hospital inpatient you may be seen by occupational therapists (OT) before you are discharged. The OT will assess you to find out if you need any special equipment or living aids to help you maintain your independence or improve your quality of life. If you are not an inpatient, you can ask your local social care services department for a care assessment to assess your needs.

The social care services offices are:

Blaby, Oadby and Wigston - **tel: 0116 278 7111**

Market Harborough - **tel: 01858 465331**

Charnwood - **tel: 01509 266641**

Melton Mowbray - **tel: 01664 564698**

Hinckley and Bosworth - **tel: 01455 636964**

North West Leicestershire - **tel: 01530 275200**

Rutland County Council - **tel: 01572 722577**

Leicester - **tel: 0116 253 1191**

British Red Cross Disabled Living Centre: The Disabled Living Centre at Aquis House, 211 Belgrave Gate, Leicester, LE1 3HT has a permanent display of daily living aids and equipment to promote independence. They offer free, impartial advice, information and assessment to people with disabilities, the elderly, carers and health professionals.

A referral is not required. Assessment is by appointment only.
Monday – Friday, 9.00 am – 4.15 pm on **0845 373 0217** or
dlcinfo@redcross.org.uk

British Red Cross Independent Living Products Shop at 113 Clarendon Park Road, Leicester, LE2 3AH stocks extensive range of equipment to improve the quality of life for elderly and disabled people on **0116 244 9049**. Monday – Friday: 9.00am – 5.00pm, Saturday: 9.00am – 4.30pm.

British Red Cross also provides a dial-a-wheelchair service providing manual wheelchairs on short-term loan (up to two months). This service is available from 244 London Road, Leicester, LE2 1RN **tel: 0116 270 0210**. Monday: 10.00am – 4.00pm

The Disabled Living Foundation – **www.dlf.org.uk** is a national charity that provides free, impartial advice about all types of daily living equipment for disabled adults and children, older people, their carers and families on **0845 130 9177**.

Carers

Leicestershire has its own **carers project** which aims to provide carers with a local contact who can supply information, advice and support. The project also runs quarterly forums every year bringing carers together to enjoy each other's company and meet organisations and individuals providing support.

Carers development workers are located around the county and each team offers a variety of practical help, support, information and advice. Contact your local office for further details of the services and help available.

Voluntary Action Blaby District: Sandra Stocks **tel: 0116 272 7669**
email: carers@vabd.org.uk

Voluntary Action Charnwood: Nita Patel **tel: 01509 631783**
email: nita.patel@voluntaryactioncharnwood.org.uk

Voluntary Action Melton: Helen Brocklehurst **tel: 01664 485304**
email: Helenb@voluntaryactionmelton.org.uk

Voluntary Action Rutland: Gill Huddleston **tel: 01572 720052**
email: gill@claspthecarerscentre.org.uk

North West Leicestershire CVS: Sarah Houlth-Eltingworth
tel: 01530 510515 email: sarahhe@nwlcv.org.uk

Oadby and Wigston Community Action: Sarah Lambrianou
tel: 0116 281 0026 ext.28 email: ksmith@vaow.org.uk

Voluntary Action South Leicestershire runs a carers telephone befriending Service, where carers enjoy a weekly call from a volunteer befriender giving them time to talk to someone confidentially outside the family. If you care for someone and would like more information to help you in your caring role, contact either Jacqui Mowson on **01858 439263** or Diane Claridge on 01858 439262. The carers project is based at Voluntary Action South Leicestershire, The Settling Rooms, St, Mary' Place, Market Harborough, Leicestershire LE16 7DR. **email:jmowson@vasl.org.uk**

Advice

Citizens Advice Bureau: www.citizensadvice.org.uk gives advice on debt, benefits, housing, employment and other legal rights.

Leicester - **tel: 0116 285 2801**

North West Leicestershire - **tel: 01530 454751**

South Leicestershire (Blaby, Lutterworth, Market Harborough) and outreach venues - **0844 848 9009** Debtline - **tel: 0844 248 0040**

Melton - **tel: 01664 484050**

Charnwood (Loughborough) - **tel: 01509 267376**

Hinckley - **tel: 0844 826 9710**

Shepshed - **tel: 01509 506663**

Rutland - **tel: 0845 120 3705**

Mosaic, Shaping Disability Service (Leicester) - tel: 0116 251 5565 Helpline: 0116 262 6900 textdirect: 18001 0116 251 5565.

Voluntary Action Leicester Shire provides information and support for voluntary and community groups and volunteers in Leicester city and various venues across Leicestershire. See their website, **www.valonline.org.uk** for more information or email **helpline@valonline.org.uk** or telephone the helpline on **0116 257 5050**.

Voluntary Action Blaby District - **tel: 0116 272 7669**

Voluntary Action Oadby and Wigston - **tel: 0116 281 0026**

Voluntary Action South Leicestershire - **tel: 01858 432014**

NW Leicestershire CVS - **tel: 01530 510515**

Voluntary Action Charnwood - **tel: 01509 631750**

Voluntary Action Melton - **tel: 01664 483043**

Voluntary Action Hinckley and Bosworth - **tel: 01455 633002**

Shopping

Shopping can be difficult if you find it hard to get around because of your condition. But there are local shopmobility schemes that provide or loan disability equipment to help, such as mobility scooters.

Leicester Shopmobility operates from two locations in the heart of the city:

Highcross Shopping Centre - **tel: 0116 253 2596**;

Haymarket Shopping Centre - **tel: 0116 253 7125**

Further information can be found at **www.leicester.gov.uk/shopmobility** or for details and contacts of other Shopmobility schemes, visit **www.shopmobility.org**

Melton Mowbray - **tel: 01664 480677**

Market Harborough - **tel: 01858 410864**

Hinckley - **tel: 07982 302 780**

Fosse Park - **tel: 0116 263 0600**

Coalville - **tel: 07982 706 285**

Loughborough - **tel: 01536 412 886**

Benefits and financial help

Many people find that facing a long-term illness affects their finances and can cause money problems. Several local organisations offer information and advice about benefits, grants and loans you may be able to obtain.

Another useful source of information is the Government citizens' information website, **www.direct.gov.uk**

Benefit Enquiry Line: Confidential advice and information for people with disabilities, their carers and families about social security benefits, **tel: 0800 882200**

Leicester Money Advice: Free debt service which provides money advice and counselling for people who live in the city, **tel: 0116 242 1120**

Welfare Rights Advice Line. Telephone advice about benefits to people with a mental health problem and their carers, **tel: 0116 225 62 22**

Age Concern: Offers practical help, advice and information about services for older people. Age Concern Leicester has its own Welfare Rights Officer on **tel: 0116 222 0555**. Other officers can be contacted at:

Leicester, Leicester-Shire and Rutland - **tel: 0116 299 2233**

Lutterworth - **tel: 01455 557116**

Oadby and Wigston - **tel: 0116 288 5203**

Hinckley and Bosworth - **tel: 01455 619519**

It's worth checking that you're claiming everything that you are entitled to: **www.entitledto.co.uk** or **[www.direct.gov.uk/en/MoneyTaxAndBenefits/ BenefitsTaxCreditsAndOtherSupport](http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport)**

Your choice...

You have the right to be treated where and when you choose.

For instance, if you needed hospital treatment, in the majority of cases you can pick the hospital of your choice for your treatment, which is right for you and your family.

Your doctor or health team would discuss the choice with you, so that you have the right information to make the decision that is right for you.

You might want to choose a hospital closer to family or friends, or a big teaching hospital. If you needed treatment, such as an operation, you might want to delay it to avoid a special occasion. But the choice is yours!

You can find out more at:

- Your GP practice
- Libraries
- **www.nhsdirect.nhs.uk**
- **NHS Direct Interactive** on digital satellite TV
- **NHS Direct** on **0845 4647**
- **www.nhs.uk**
- **www.healthspace.nhs.uk**
- **www.chooseandbook.nhs.uk**
- **www.healthcarecommission.org.uk**
- **www.patientopinion.org.uk**

NHS Choices

A wide range of information and advice about your condition and how to your choices about your care and treatment is available on the NHS website, '**NHS Choices**', or from the NHS telephone helpline, '**NHS Direct**'.

'**NHS Choices**' on **www.nhs.uk** is a wide ranging comprehensive guide and directory that gives:

- Medical advice about most conditions
- Services from GPs to gyms, doctors to dentists, midwives to memory problems
- 'All you need to know' guides covering 750 conditions and treatments
- Carers help and advice
- Blogs to talk to the experts and other patients
- Feedback from other patients
- Up to date medical news and views on treatment and research
- Tips and help on keeping you healthy
- Benefits advice
- Links to other medical, charity and support websites
- Comparisons between hospitals to help YOU chose where YOU want to be treated

For those without internet facilities, the same information and more is available from 'NHS Direct' – the 24 hours a day every day of the year helpline.

Trained staff are available round the clock to give advice and information on all aspects of health - from instant help with immediate symptoms or problems and where to get treatment; to details of walk in centres, clinics, local organisations, support and help on **0845 46 47**.

This publication has been jointly produced by the four NHS organisations in Leicester, Leicestershire County and Rutland. Printed copies are available by contacting any of the organisations:

- **NHS Leicestershire County and Rutland**

Lakeside House, 4 Smith Way, Grove Park, Enderby,
Leicestershire, LE19 1SS

tel: 0116 295 7689

or **email: communications@lcr.nhs.uk**

- **NHS Leicester City**

St John's House, 30 East Street, Leicester, LE1 6NB

tel: 0116 295 1100/1400

or **email: enquiries@leicestercity.nhs.uk**

- **Leicestershire Partnership NHS Trust**

George Hine House, Gipsy Lane, Leicester, LE5 0TD

tel: 0116 225 6485

or **email: feedback@leicspt.nhs.uk**

- **University Hospitals of Leicester NHS Trust**

University Hospitals of Leicester NHS Trust Headquarters,
Gwendolen House, Gwendolen Road, Leicester LE5 4QF

tel: 0116 258 8963

or **email: communications@uhl-tr.nhs.uk**

For further information or comments, or if you would like to contribute to the production of this document or further publications, please contact any of the above trusts.

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The NHS trusts listed above cannot be held responsible for any information provided by non-NHS organisations detailed in this document