



Useful sources of information, help and advice for people with chronic kidney disease

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To see all of our current patient information leaflets please visit
www.uhb.nhs.uk/patient-information-leaflets.htm

Introduction

Kidney patients often feel they need some extra help and information at some stage during their treatment.

You or your family, friends and carers may need some information or advice about your kidneys and treatment, or perhaps you have a practical question that needs answering. This leaflet gives you other sources of information and advice that you may find helpful.

These sources include:

- Local and national support groups
- Useful websites
- Books
- Other useful organisations

Support groups

There are a number of self-help, patients' associations and support groups:

- **Queen Elizabeth Hospital Birmingham Peer Support**
Kidney patients trained to help other kidney patients by using their own experience of kidney disease. We try to match you to someone who has similar experiences to you, to offer you advice and support.

Email: kidneysupport@uhb.nhs.uk

Alternatively you can contact one of the satellite dialysis co-ordinators who will pass on your message. Please call 0121 371 3006 between 08:00-16:00 Monday-Friday.

- **British Kidney Patient Association (BKPA)**

Telephone: 01420 472021/2

Fax: 01420 475831

www.britishkidney-pa.co.uk

- **National Kidney Federation**
Telephone: 01909 544999
Fax: 01909 401723
Helpline: 0845 601 0209
www.kidney.org.uk
- **Queen Elizabeth Kidney Patients' Association**
www.kidneymatters.co.uk
- **Transplant Support Network**
Advice line: 0800 027 4490
www.transplantsupportnetwork.org.uk
- **Polycystic Kidney Disease Charity**
Helpline: 01388 665004
www.pkdcharity.co.uk
- **Expert Patient Programme**
Telephone: 01886 833186
www.expertpatients.nhs.uk
- **Diabetes UK**
Telephone: 0207 424 1000
Fax: 0207 424 1001
Helpline: 0845 1202 960
www.diabetes.org.uk

Other useful kidney organisations

- **Kidney Research UK**
Telephone: 0845 300 1499
www.kidneyresearchuk.org
- **Kidney Alliance**
Telephone: 01483 724 472
www.kidneyalliance.org
- **NHS Blood and Transplant**
Telephone: 0117 975 7575

Fax: 0117 975 7577
www.uktransplant.org.uk

- **Kidney Care Matters Online** is a communications tool from NHS Kidney Care that aims to keep you informed and aware of what is happening across England to ensure the Renal National Service Framework is met.

Visit: www.kidneycare.nhs.uk

- **Renal PatientView** provides online information about renal patients' diagnosis, treatment and latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world. PatientView is available to you if you wish to participate.

www.renalpatientview.org

- **'Living with Kidney Disease: What should you know'** is the title of two DVDs aimed at raising awareness and education to support anyone who has been told by their doctor that they have kidney damage. The first DVD is for people who have just been diagnosed with chronic kidney disease. The second DVD offers practical advice for people with advanced kidney disease. There are options to view the DVDs with subtitles in English and audio in Bengali, English, Gujarati, Hindi, Punjabi and Urdu. Copies of the DVD can be obtained from Kidney Research UK's health information line.

Telephone: 0845 300 1499

Email: kidneyhealth@kidneyresearchuk.org

- **West Midlands Renal Network** provides information about local kidney services.

www.wmrn.co.uk

- **The Kidney Patient Guide** provides information for people with kidney failure.

www.kidneypatientguide.org.uk

- **British Journal of Renal Medicine** is published four times a year and each issue includes a patient information section.
www.bjrm.co.uk
- **RenalInfo** offers help, advice and support to people with kidney disease.
www.renalinfo.com
- **Renal Tsar's blog** gives updates from the National Clinical Director for kidney care
www.renaltsar.blogspot.com

Useful websites

- **The British Heart Foundation**
www.bhf.org.uk
- **Eurodial** is an international dialysis organisation dedicated to the care and mobility of dialysis patients in Europe.
www.eurodial.org
- **Global Dialysis** provides details of holiday and travel information for dialysis patients.
www.globaldialysis.com
- **NHS Direct**
Telephone: 0845 4647
www.nhsdirect.nhs.uk
- NHS Choices for information about a wide range of health topics.
www.nhs.uk/Pages/HomePage.aspx
- **Department of Work & Pensions** provides confidential advice and information about social security benefits and how to claim them.
Telephone: 0800 882200 (free)
Textphone: 0800 243355 (free)
Website: www.dwp.gov.uk

- **Citizens Advice Bureau** provides free, independent and confidential advice.
www.citizensadvice.org.uk
- **Age UK** provides additional support and guidance for older people on their website.
www.aceuk.org.uk
- **Healthcare Travel Costs Scheme** provides basic information about getting financial help if you're on a low income
www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/DH--_075759
- **Macmillan Cancer Support** provides practical, medical, emotional and financial support.
www.macmillan.org.uk
- **HealthWatch England** is a new independent national consumer champion organisation for users and carers across health and social care.
Locally this is currently being provided by Birmingham Local Involvement Network.
www.birminghamlink.org
- **Birmingham Institute for the Deaf (BID)** is a registered charity supporting people who are deaf and hard of hearing.
www.bid.org.uk
Phone (voice) 0121 246 6100

Books

The following books may be useful.

Juliet Auer, *Living Well With Kidney Failure*. Class Publishing, 2004

Helena Jackson, Annie Cassidy and Gavin James, *Eating Well With Kidney Failure*. Class Publishing, 2005

Dr Andy Stein, Dr Rob Higgins and Janet Wild, *Kidney Transplants Explained*. Class Publishing, 2008

Dr Andy Stein and Janet Wild, *Kidney Failure Explained*. Class Publishing 2007

You will also find local information leaflets within the different renal departments. A wide range of patient information leaflets and fact sheets are available through the University Hospitals Birmingham NHS Trust website and can be accessed via

www.uhb.nhs.uk/patient-information-leaflets.htm

Patient Advice and Liaison Services (PALS) act on behalf of their service users when handling patient and family concerns. They liaise with staff, managers and, where appropriate, other relevant organisations, to negotiate speedy solutions and to help bring about changes to the way services are delivered. The PALS team can be contacted on 0121 371 3280 (09:00–17:00 Monday – Friday) or you can email them at PALS@uhb.nhs.uk

The Chaplaincy team can be contacted on 0121 371 4574 or you can email them at Chaplaincy@uhb.nhs.uk

An interpreting service is available for both in-patients and out-patients requiring information in a foreign language. To contact the interpreting team please call 0121 627 7884 (09:00 – 17:00 Monday – Friday).

There is a social worker who provides advice on how to claim benefits for people with kidney problems. Please call the social work department on 0121 371 4593 between 09:00-17:00 Monday-Friday.

If you have any questions about emergency hospital transport please call 0121 415 3780.

Please ask one of your nurses if you need any further information.

Useful numbers

Ward 301 (Acute Renal)	0121 371 3096
Ward 301 (Chronic Renal)	0121 371 3011
Old Renal Dialysis Unit	0121 627 2910
Aston Cross Dialysis Centre	0121 333 6766
Tipton Dialysis Centre	0121 557 8313
City Hospital Renal Dialysis Unit	0121 507 4014
Kings Norton Dialysis Centre	0121 486 4280
Lichfield Renal Unit	01543 262363
Kidderminster Renal Unit	01562 826370
Hereford Dialysis Centre	01432 277929
Woodgate Valley Dialysis Centre	0121 421 0090
Worcester Dialysis Centre	01905 721 940
CAPD	0121 627 2515
Monday-Friday 09:00-17:00	
Pre-dialysis	0121 627 5752
Monday-Friday 09:00-17:00	



The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk or call 0121 627 7803

Renal Unit
Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston,
Birmingham, B15 2WB
Telephone: 0121 627 2000
