

Queen Elizabeth Hospital Birmingham



Part of University Hospitals Birmingham

NHS Foundation Trust



Where can I find more
information and advice about
chronic kidney disease?

Delivering the best in care

UHB is a no smoking Trust

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 Renal websites
- Some useful Renal Leaflets, DVDs and Books
- Other useful organisations
- Useful contact numbers

Support Groups

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

Local

- **Queen Elizabeth Hospital Birmingham Peer Support**

Peer support is delivered by trained kidney patients who offer support and advice by using their experiences of kidney disease. You will be matched to someone who has had a similar experience to you.

Telephone: 0121 627 5752, 0900:1700hr Monday to Friday.

E-mail: kidneysupport@uhb.nhs.uk

- **Queen Elizabeth Kidney Patients' Association**

www.kidneymatters.co.uk

- **Renal Psychology & Counselling**

Managing a health condition, such as chronic kidney disease, can impact on your mood, confidence and self-esteem. This service works to help people cope better with these emotions. We recognise family members may also be affected so this service extends to them too. You can ask your nurse or consultant to refer you or you can self-refer.

Telephone: 0121 371 5851 and book via Dolores Tait.

National

- **British Kidney Patient Association (BKPA)**
Telephone: 01420 541424
E-mail: info@britishkidney-pa.co.uk
- **National Kidney Federation**
Telephone: 01909 544999
Helpline: 0845 601 02 09 which is free from UK land lines.
www.kidney.org.uk
- **NHS Blood & Transplant**
Organ Donor Line: 0300 123 23 23
www.organdonation.nhs.uk
- **Polycystic Kidney Disease Charity**
Support line: 0300 111 1234
www.pkdcharity.org.uk
- **Expert Patient Programme**
www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/expert-patients-programme.aspx

Useful Renal Websites

- **PatientView** provides you with online information about your diagnosis, treatment and test results. Patients can share this information with anyone they want, and view it from anywhere in the world.
Telephone: 0117 323 8209 www.patientview.org/#/
- **The Kidney Patient Guide** provides vast information about how to deal with the practicalities of chronic kidney conditions. It includes how to tell family and friends, manage your symptoms, learn more about treatments, deal with the emotional effects, modify your diet, organise holidays, arrange for carers and join support groups.
www.kidneypatientguide.org.uk

- **NHS - Living with chronic kidney disease** covers a wide range of information from personal experiences of renal disease to the practicalities of organising holidays and benefits.
www.nhs.uk/Conditions/Kidney-disease-chronic/Pages/living-with.aspx
- **British Journal of Renal Medicine**
www.bjrm.co.uk
- **Kidney Research UK**
Telephone: 0300 303 1100
www.kidneyresearchuk.org
- **Renal Tsar's blog** provides updates from the National Clinical Director for kidney care
www.renalsar.blogspot.com
- **West Midlands Renal Network** provides information about local kidney services.
www.wmrn.co.uk

Useful Renal Leaflets, DVDs & Books

Leaflets

There are a wide range of patient information leaflets and fact sheets available in renal departments, and on the University Hospitals Birmingham NHS Trust website.

www.uhb.nhs.uk/renal-pi.htm

DVDs

- **'Living with Kidney Disease.'** Collection of 3 DVDs (a small charge applies)

The DVDs help raise awareness and support anyone who has been told by their doctor that they have kidney damage. The DVDs are available with English subtitles and an audio in Bengali, English, Gujarati, Hindi, Punjabi and Urdu.

Telephone: 01227 811 671 kidneyhealth@kidneyresearchuk.org

- **'Living Well with Kidney Disease' (Free DVD)**

A series of DVDs with companion booklets are available in English, Spanish and close-captioned text. They help you and your families learn about kidney failure and its treatment.

These are the topics covered:

- What is kidney failure?
- How kidney failure affects your body
- Kidney transplant
- Peritoneal dialysis
- Haemodialysis
- Living well

www.kidney.org/professionals/KLS/lwkwf

Books

- **Living Well with Kidney Failure: A Guide to Living Your Life to the Full (Class Health)**

Juliet Auer, Richenda Milton-Thompson and David Woodroffe. 2004

- **Eating Well With Kidney Failure (Class Health).**

Helena Jackson, Annie Cassidy and Gavin James. 2006

- **Kidney Transplants Explained: Everything You Need to Know.**

Andy Stein, Rob Higgins and Janet Wild. 2008

- **Kidney Failure Explained: Everything You Always Wanted to Know About Dialysis and Kidney Transplants But Were Afraid to Ask (Class Health)**

Andy Stein and Janet Wild. 2010

Other Useful Renal Websites

- **Freedom The Dialysis Holiday Specialists**
Telephone: 01509 815999
www.holidaydialysis.co.uk
- **Eurodial** is an international dialysis organisation dedicated to the care and mobility of dialysis patients in Europe.
www.idotourisme.com/
- **Global Dialysis** provides details of holiday and travel information for dialysis patients.
www.globaldialysis.com
- **Department of Work & Pensions** provide a tool called 'Benefits Adviser' which shows you benefits you are entitled to and how to claim them.
Telephone: 0844 856 9900
www.gov.uk
- **Citizens Advice Bureau** provides free, independent and confidential advice.
www.citizensadvice.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.healthwatchbirmingham.co.uk
- **Social Worker Access**
A social worker can provide advice on adult social care. This is available from your local council in the area you live in and benefits advice can be provided.

Other Useful Supporting Services

Local

- **Birmingham Institute for the Deaf (BID)** is a registered charity supporting people who are deaf and hard of hearing.
Telephone (voice) 0121 246 6100
www.bid.org.uk
- **Patient Advice and Liaison Services (PALS)** act on behalf of patients and their families to liaise with health care service providers to deal with concerns and complaints that may arise during their care.
Telephone: 0121 371 3280 09:00–17:00 Monday – Friday
E-mail: PALS@uhb.nhs.uk
- **Multi-faith Chaplaincy Care**
Telephone: 0121 371 4574
E-mail: Chaplaincy@uhb.nhs.uk
- **Interpreter Services and Language Support**
Available for both in-patients and out-patients requiring information in a foreign language.
Telephone: 0121 627 7884, 09:00 – 17:00 Monday – Friday.

National

- **Age UK**
Telephone: 0800 169 2081 www.ageuk.org.uk
- **Blood Pressure UK**
Telephone: 020 7882 6255 www.bloodpressureuk.org
- **Diabetes UK**
Tel: 0345 123 2399 www.diabetes.org.uk
- **Macmillan Cancer Support**
Telephone: 0808 808 0000 www.macmillan.org.uk

Useful numbers

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|-----------------------------------------------|---------------------|
| Chronic Kidney Disease Community Support Team | 0121 627 5752* |
| Renal Dietitians | 07880 473 8797* |
| Peritoneal Dialysis Team | 0121 627 2515* |
| Home Haemodialysis | 0121 371 8340* |
| Haemodialysis Co-ordinators | 0121 371 3002/3013* |
| Ward 301 (Acute Renal) | 0121 371 3096 |
| Ward 301 (Chronic Renal) | 0121 371 3011 |
| Smethwick Dialysis Unit | 0121 371 8321 |
| Greatbridge Kidney Treatment Centre | 0121 557 5538 |
| Kings Norton Kidney Treatment Centre | 0121459 9002 |
| Hereford Kidney Treatment Centre | 01432 274 603 |
| Worcester Dialysis Unit | 01905 721940 |
| Woodgate Dialysis Unit | 0121 421 0090 |
| Kidderminster Dialysis Unit | 0156 282 6370 |
| Sparkhill Dialysis Unit | 0121 766 0470 |
| Llandrindod Wells Dialysis Unit | 01597 827940 |
| Lichfield Dialysis Unit | 0154 325 0976 |
| Hospital Transport | 0121 307 9118* |

*09:00 – 17:00

Monday – Friday



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 2GW

Telephone: 0121 627 2000
