Information about Polycystic Kidney Disease

What is polycystic kidney disease? (PKD)

- A common inherited kidney condition that affects males and females equally.
- Cysts develop in each kidney – from a few to many hundred, each one is like a blister and contains clear fluid.
- The kidneys can become very large. Individual cysts can also become very big.
- These cysts can also appear in the liver and pancreas.
- It may lead to kidney failure but liver and pancreatic function do not usually suffer.
- Each child of an affected individual has a 50% chance of inheriting the disease.
- Each sibling of an affected individual has a 50% chance of inheriting the disease.
- PKD can occur spontaneously i.e. without a family history of the condition.
- Genetic testing for polycystic kidney disease is now possible. There are two genes that can be at fault; PKD1 (in majority) and PKD2.

Complications of polycystic disease

Polycystic kidney disease can cause complications although not all patients will get all or any of these.

- **Discomfort** due to enlarged kidneys, bleeding into a cyst or infection in a cyst.
- **High blood pressure** which will need medication.
- **Blood** in the urine.
- **Protein** in the urine.
- **Kidney stones.**
- **Urinary tract or cyst infections.**
- **Decreased kidney function**: the rate of deterioration can vary but may lead to kidney failure requiring dialysis or transplantation.

- **Cerebral aneurysm**: weakness in the wall of a blood vessel in the brain.

- **A heart murmur**: this is rarely serious.

- **Diverticulitis**: weakness in the bowel wall.

**Diagnosis and treatment of polycystic kidney disease**

**Diagnosis** of the condition is made from one or more of the following:

- Family history.
- Physical examination.
- Ultrasound scan of the kidneys.
- Blood tests.
- Genetic testing.

**Treatment** for polycystic kidney disease is aimed at delaying loss of function of the kidneys by:

- Monitoring and treating high blood pressure which will require tablets.
- Drinking more water.
- Treating urinary tract infections promptly with antibiotics.
- Avoiding some drugs, for example ibuprofen, if possible.
- Tablets to reduce protein in the urine (ACE inhibitors).
- Monitoring cholesterol and treating raised levels with tablets.
- Some patients may be eligible for treatment with Tolvaptan to slow progression of PKD. Please discuss with the doctor at your appointment.
- We can also offer further advice and genetic counselling if required.

**Where can I get further information?**

- In the first instance please call 01223 284568 (renal secretariat)
- The Specialist Nurse can be contacted on 01223 348745
Additional sources of information

- Polycystic Kidney Disease booklet – Available in Renal Genetics Clinic
- [www.kidney.org.uk](http://www.kidney.org.uk)
- [www.pkdccharity.co.uk](http://www.pkdccharity.co.uk)
- [www.rarerenal.org](http://www.rarerenal.org)
- [www.merck.com](http://www.merck.com)
- Addenbrookes Kidney Patient Association (AKPA) contact details available from the Renal Genetics Clinic.

- There is a lot of information available via the web but not all of this may be relevant to you and may prove frightening. If you have any concerns please discuss this with us in clinic.

- As part of this clinic we are developing patient information about some disorders of the kidney. We would like to include patients’ views and experiences in this.

- If you would like to be involved as a patient representative, please let us know in clinic or on the contact number above.

Renal Genetics and Tubular Disorders Clinic

Box No. 118
Direct dial: 01223 256318

**Consultants**

Professor Fiona Karet  Nephrology  01223 762617
Dr Richard Sandford  Clinical Genetics  01223 348845
Dr Anita Sarker  Biochemistry  01223 586820
Mr Oliver Wiseman  Urology  01223 586593
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For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:
If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.

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Authors Renal Genetics and Tubular Disorders Clinic
Pharmacist n/a
Department Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ www.cuh.org.uk
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