

Renal Genetics and Tubular Disorders Clinic



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.
- 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 for some families.

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 (under development).

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.
- Treating urinary tract infections promptly with antibiotics.
- Avoiding some drugs, for example, ibuprofen.
- Tablets to reduce protein in the urine (ACE inhibitors).
- Monitoring cholesterol and treating raised levels with tablets.
- We can also offer further advice and genetic counselling if required.

Where can I get further information?

- The Clinic Sister is Caroline Robinson. You can contact her by:
- phone: 01223 348745
- e-mail: caroline.robinson@addenbrookes.nhs.uk

Additional sources of information

- Polycystic Kidney Disease booklet – Available in Renal Genetics Clinic
- www.kidney.org.uk
- www.pkdcharity.co.uk
- 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.

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Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or

patient.information@addenbrookes.nhs.uk



Document history

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