Adult Polycystic Kidney Disease

This leaflet explains what APKD is, how it may affect you and your family and how it is managed / monitored.

What is Adult Polycystic Kidney Disease (APKD)?

The kidneys develop small swellings (cysts), which fill with fluid and tend to grow over many years, replacing the normal kidney tissue. These are not cancerous but may make the kidneys very large (as big as a baby!).

How did I get it?

The condition is directly inherited from one parent. This parent must have had APKD, although it may not have been diagnosed. If you question your family, you may find other relatives who have had kidney problems. Occasionally, it may arise spontaneously.

What symptoms might I have?

There are often no symptoms; your condition may even have been picked up as a chance finding. In the kidney, the cysts may cause loin pain, blood in the urine, infection or sometimes stones. It is important to diagnose infection, so if you get any symptoms it is sensible to take a urine sample to your doctor.

You are more likely to have high blood pressure (hypertension). There is a very small risk that you may develop a problem with a heart valve or a swelling on a blood vessel. Your doctor will discuss this with you, if this is a possibility.

What treatment will I need?

You may never need any treatment at all although the majority of patients will require blood pressure medication. If your kidneys are very big and/or your kidney function declines rapidly you may be eligible to receive treatment with Tolvaptan. This drug can slow down the decline in kidney function. Your kidney doctor will discuss this treatment with you if you may benefit. Your care will be aimed at protecting the kidney function as much as possible. Your blood pressure and kidney function will be monitored once a year – more often if necessary.

Will APKD damage my kidneys?

Fifty percent of people with APKD never have any severe damage to kidney function. The other 50% will have some signs of kidney damage by the age of 50. Once damage begins, the kidneys will slowly deteriorate. Dialysis and/or transplantation is likely to be needed within 10 years of the first signs of damage. This can be delayed by careful treatment of blood pressure and infection.

Does APKD affect any other part of my body?

You may have cysts in the liver and pancreas, but these rarely seem to cause problems.

Will I pass APKD on to my children?

In the same way that you inherited the condition from one of your parents, you have a 50:50 chance of passing the condition on to any of your children. This does not mean you should avoid having children (remember, they only have a 50:50 chance of inheriting it and a 50:50 chance of damage to kidney function by the age of 50 even if they do inherit it).

Should my children be checked for APKD?

APKD can be clearly diagnosed or excluded by a simple ultrasound scan after the age of 20. Your children may like to discuss the problem with us first. The benefit of knowing you do not have the disease is obvious. The benefit of knowing you do have the disease is that you get good medical care for the condition as early as possible. The 'down' side of this is that insurance companies will take it into account and may make life insurance and mortgage policies more expensive.

Further information

The National Kidney Federation website: www.kidney.org.uk

Contacting us

Kidney Care Nurses 0118 322 7899 Victoria Ward 0118 322 7476

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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