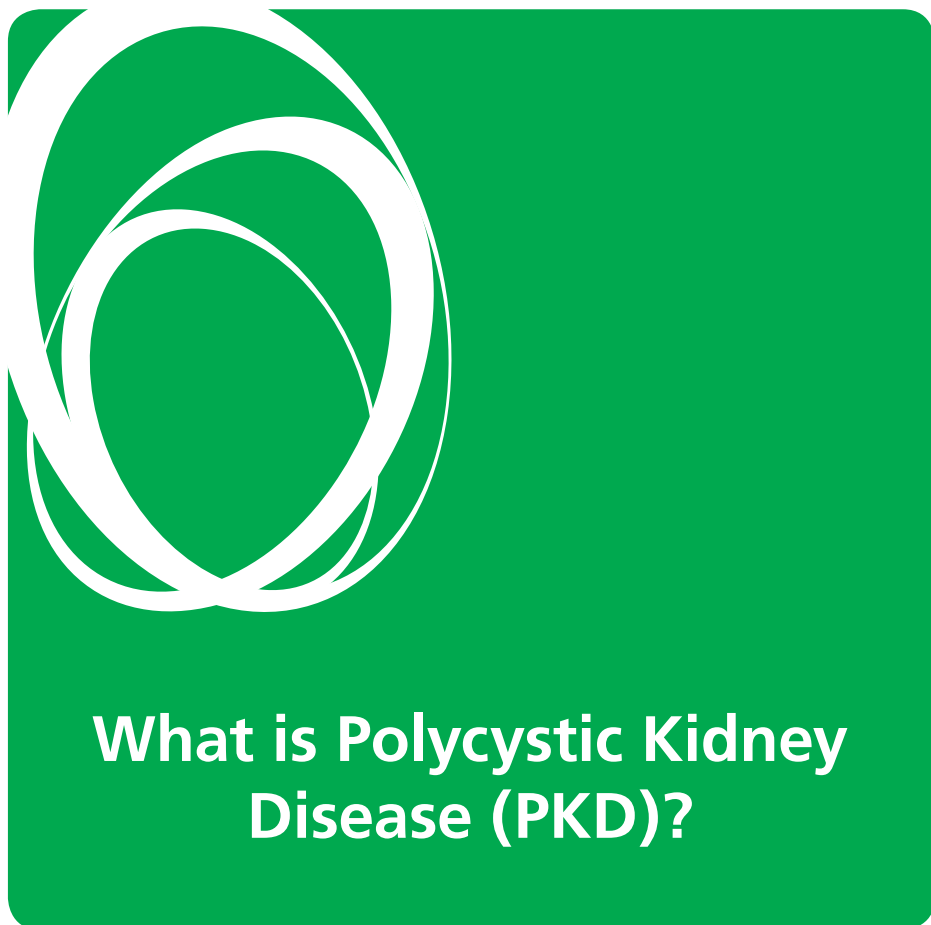


Queen Elizabeth Hospital Birmingham



Part of University Hospitals Birmingham

NHS Foundation Trust



## What is Polycystic Kidney Disease (PKD)?

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[www.uhb.nhs.uk/patient-information-leaflets.htm](http://www.uhb.nhs.uk/patient-information-leaflets.htm)

## Introduction

There are many conditions that can cause damage to your kidneys. One of the more common conditions is polycystic kidney disease. This leaflet provides information on what polycystic kidney disease is, the common signs and symptoms, how it is treated, and describes some of the complications that may occur.

If you have any questions or want more information please ask your kidney doctor or nurse.

## What is polycystic kidney disease?

Cysts are round balloon-like structures filled with fluid. Small numbers of cysts can occur normally in the kidney but in polycystic kidney disease (often just called PKD) there may be hundreds of cysts in each kidney. Although there are many types of PKD by far the most common is called autosomal dominant PKD (ADPKD) and this leaflet deals only with this type.

In ADPKD cysts start to form in the kidneys and slowly grow over a period of decades. To start with the cysts are tiny but over time they slowly grow and can become the size of an apple. As the cysts get bigger they crowd out normal healthy kidney tissue causing kidney failure. They can also cause pain, leak fluid, burst or get infected. The affected kidneys get bigger and sometimes they become 3 or 4 times the normal size.

Cysts can also form in other organs such as the liver and pancreas but fortunately these rarely cause problems.

## How is polycystic kidney disease inherited?

Polycystic kidney disease is an inherited condition that is passed down through the generations from parent to child. The child of an affected individual has a 50% chance of being affected themselves. This pattern of inheritance is called 'autosomal-dominant'. Other, rarer types of polycystic kidney disease are inherited in different ways. Occasionally polycystic kidney disease appears for the first time in an individual. In these cases there may be no other affected family members.

## Common signs and symptoms of PKD

It is quite common to have polycystic kidney disease for years without developing any symptoms or realising you have the condition. The signs and symptoms of polycystic kidney disease occur as the cysts and kidneys get bigger. Common problems include one or more of the following:

- A lump in your tummy on one or both sides
- Feeling of fullness or indigestion as the enlarged kidneys press on your stomach
- Blood in your urine
- Discomfort or pain over the kidneys
- Frequent urinary tract infections
- Raised blood pressure
- Kidney failure requiring dialysis or a kidney transplant

It is important to realise that everyone is different and therefore may experience very different symptoms. Most people with polycystic kidney disease start to get problems in middle age but rarely problems occur in childhood as well.

## How is PKD diagnosed?

Polycystic kidney disease is almost always diagnosed by a kidney scan, most commonly a kidney ultrasound. If you have family members with PKD you may be advised to have a scan to check for the presence of cysts but sometimes it is discovered accidentally if a scan is being done for another reason.

## Treatment of PKD

Normally people with polycystic disease are seen regularly by a kidney doctor at the hospital. There is currently no cure or treatment to stop polycystic kidney disease from developing. The treatment is therefore aimed at controlling symptoms and preserving your kidney function as long as possible by:

- Living a healthy lifestyle. You can help by eating a well balanced diet, taking regular exercise, stopping smoking and keeping a healthy weight
- Monitoring and keeping your blood pressure under control is important as high blood pressure can also cause your kidney function to reduce. If your blood pressure is high it will be treated with blood pressure lowering tablets. Reducing your salt and alcohol intake can help too.
- Monitoring your cholesterol levels and taking tablets if the level is raised
- Treating any urine infections with antibiotics
- Avoiding certain drugs e.g. Ibuprofen
- Monitoring your kidney function

As your kidneys get bigger they can become painful, especially if cysts burst or become infected. In some people this can become so severe that your kidney doctor may talk to you about having an operation to remove one or both of your kidneys. If you have both of your kidneys removed you will need to have dialysis treatment or a kidney transplant.

If your kidney function gets worse your kidney doctor and nurse will talk to you about the different treatments available for kidney failure.

## What are the other complications of PKD?

Some people with polycystic kidney disease can develop weaknesses of blood vessels in the brain which causes the vessels to swell (called an aneurysm). There is a risk that an aneurysm may burst and cause a bleed into the brain.

Other problems can include:

- Hernias
- Diverticular disease (small pouches in the bowel)

## Screening for PKD

If you have polycystic kidney disease you may want to let your brothers and sisters know that they could have a chance of having it. If you have children you may want them to be tested to see if they have the disease before any symptoms develop. The best way of doing this is to talk to your doctor to discuss who in the family might be affected and what tests are available. The simplest test is a kidney ultrasound scan but this needs to be carefully done to make the results meaningful which is why it is best organised by a specialist. A specialist in genetics will be able to help explain the way the disease is inherited and whether any special DNA tests could help in your family.

## The Future

Our understanding of polycystic kidney disease has moved forwards enormously over the last few decades and we hope to having some specific treatments available over the next five to ten years that may slow or even stop the disease from progressing. Although people with advanced disease today may not benefit, we hope that children with the condition will have the option of some effective treatments in the future.

If you have any questions please speak with your kidney doctor.

## Other Sources of Information

The National Kidney Federation [www.kidney.org.uk](http://www.kidney.org.uk)

NHS Kidney Care [www.kidneycare.nhs.uk](http://www.kidneycare.nhs.uk)

Kidney Research UK [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

Kidney Alliance [www.kidneyalliance.org](http://www.kidneyalliance.org)

West Midlands Renal Network website [www.wmrn.co.uk](http://www.wmrn.co.uk)

NHS Choices [www.nhs.uk](http://www.nhs.uk)

NHS Direct [www.nhsdirect.nhs.uk/](http://www.nhsdirect.nhs.uk/) or call 0845 4647 (24 hours a day).

The PKD Charity supports people with polycystic kidney disease. Visit their website: [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) or call their helpline on: 0300 111 1234.

A wide range of patient information leaflet 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](http://www.uhb.nhs.uk/patient-information-leaflets.htm)

## Useful numbers

Pre-dialysis (Monday-Friday 09:00-17:00)      0121 627 5752



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

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