



YOUR GUIDE TO LIVING WITH  
**POLYCYSTIC  
KIDNEY  
DISEASE**



**PKD FOUNDATION  
OF CANADA**

*For Research in  
Polycystic Kidney Disease*

[www.endpkd.ca](http://www.endpkd.ca)

# ABOUT PKD

## WHAT IS POLYCYSTIC KIDNEY DISEASE?

Polycystic kidney disease (PKD) is a group of genetic diseases that cause fluid-filled cysts to develop in internal organs, primarily affecting the kidneys. Over time, these cysts grow and multiply, causing the kidneys to increase sometimes dramatically in size.

### THERE ARE TWO PRINCIPAL HEREDITARY FORMS OF PKD:

Autosomal Dominant PKD (ADPKD) is one of the most common, life-threatening genetic diseases, affecting approximately 1 in 500 worldwide. Symptoms usually develop between the ages of 30 and 40, but they can begin earlier. Parents affected by ADPKD have a 50 percent chance of passing it on to each of their children. About 10 percent of cases are due to new mutations in the genes that cause PKD.

Autosomal Recessive PKD (ARPKD) is a relatively rare inherited form, affecting 1 in 20,000. Symptoms usually begin in the earliest months of life, even in the womb. Parents, who are carriers of the ARPKD gene, have a 25 percent chance of passing the disease on to each of their children, but have no evidence of kidney disease themselves.

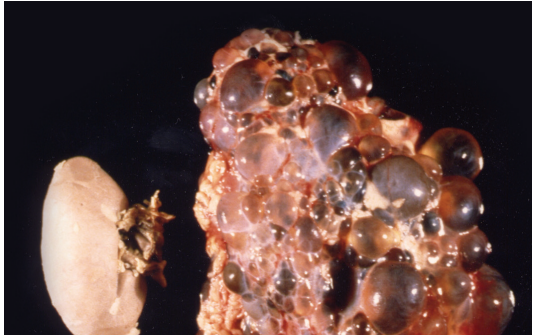
### WHERE ARE MY KIDNEYS AND WHAT DO THEY DO?

Everyone has two bean-shaped kidneys, each the size of a fist, located in the middle of the back, below the rib cage. The kidneys perform several important functions, including:

- Removing waste products from the body;
- Balancing the body's fluids;
- Releasing hormones that regulate blood pressure (renin);
- Producing an active form of vitamin D that promotes strong, healthy bones (calcitriol); and
- Controlling the production of red blood cells (erythropoietin).

### HOW IS KIDNEY FUNCTION DETECTED?

The best routine test of kidney function is a blood test to measure creatinine. Creatinine is a waste product of the kidney. As kidney function becomes impaired, creatinine level rises. Normal is approximately 0.6 – 1.3 mg/dl. Your doctor uses these test results along with other factors to calculate your glomerular filtration rate (GFR). Your GFR tells how much kidney function you have. Normal is approximately 100ml/min. GFR levels vary with age and sex; values lower than 80 signify declining kidney function.



### **IN ADDITION TO KIDNEY CYSTS, WHAT ARE THE SYMPTOMS OF ADPKD?**

- High blood pressure (Hypertension) – Normal BP is 120/80;
- Constant or intermittent pain in the back and the side of the stomach;
- Frequent urinary tract infections;
- Blood in the urine (hematuria);
- Kidney stones;
- A family history of kidney problems; and
- Heart problems and/or stroke.

### **HOW IS ADPKD DIAGNOSED?**

- There is a family history of ADPKD.
- The patient exhibits several signs and symptoms associated with ADPKD.
- Kidney imaging studies:
  - Ultrasound, which passes sound waves through the body to create a picture of the kidneys, is used most often. Ultrasound imaging does not use any injected dyes or radiation and is safe for all patients, including pregnant women.
  - CT scans and MRI also can detect cysts, but are more expensive and have more associated risks, such as radiation.

### **WHAT ARE OTHER COMPLICATIONS OF ADPKD?**

Although each patient's experience is unique, possible complications of ADPKD may include:

- Liver and pancreatic cyst formation;
- Mitral Valve Prolapse (MVP) – a condition where the valve separating the top and bottom of the left side of the heart does not close properly, which can cause blood to leak back to the top part of the heart;
- Aneurysms – bulges in the walls of blood vessels – in the brain;
- Left ventricular hypertrophy – thickening of the heart muscle;
- Hernias – often near the groin (inguinal) or navel (umbilical); and
- Diverticulosis – small pouches bulge outward through the colon.

# LIVING WITH PKD

## WHAT OPTIONS ARE THERE FOR RELIEVING SYMPTOMS AND PROLONGING LIFE?

- Medicine, diet and exercise to control blood pressure
- Medicine and surgery to reduce pain
- Healthy lifestyle including smoking cessation, healthy diet, regular exercise and maintaining a healthy weight
- Antibiotics to resolve infections
- Dialysis to replace functions of failed kidneys
- Kidney transplantation

## IS THERE A CERTAIN DIET I SHOULD FOLLOW?

Nutrition can be an important factor in controlling your blood pressure and prolonging the health of your kidneys. To be considered a KidneyWise™ food, a product must meet all of the following nutritional levels, which are based on a standard serving size as specified by the FDA for an individual food. A serving of the food product must:

- Be low in potassium (less than 200 milligrams);
- Be low in phosphorus (less than or equal to 100 milligrams);
- Be low in fat (less than or equal to 3 grams);
- Be low in cholesterol (less than or equal to 20 milligrams);
- Be a significant fiber source (contain 3 or more grams of fiber);
- Be low in sodium (less than or equal to 140 milligrams);
- Contain at least 10 percent of the Daily Value of one or more of these naturally occurring nutrients: Vitamin A, Vitamin D, Vitamin C, B- vitamins or Iron; and
- Contain the essential fatty acid-Omega 3's.

## WHY IS BLOOD PRESSURE CONTROL IMPORTANT?

High blood pressure may further damage and scar the kidney and is also a risk factor for heart disease and stroke.

## HOW LOW SHOULD MY BLOOD PRESSURE BE?

Although the optimal blood pressure level for PKD is still unknown, as a rough rule, blood pressure should be about 130/80 or lower. The HALT PKD study may shed some light on this issue by comparing the effects of having a blood pressure at 130/80 versus 110/70.

## WHAT IS THE BEST BLOOD PRESSURE MEDICATION?

Although patients should always consult their health care team before taking any new medications, ACE inhibitors or angiotensin receptor blockers are typically recommended because there is increased activity of the rennin angiotension system in ADPKD.



### **ARE THERE CLINICAL TRIALS I CAN PARTICIPATE IN?**

Currently there are a number of clinical trials regarding PKD you may be eligible to be involved in. Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available and help others by contributing to medical research. For a complete list of clinical trials for PKD patients, visit [www.endpkd.ca](http://www.endpkd.ca).

### **ARE THERE CERTAIN MEDICATIONS I SHOULD AVOID?**

Before taking anything that could harm your kidneys or affect your blood pressure, weigh the risks and benefits with your physician. In general, it is best to avoid the following over the counter and prescription medications:

- Non-steroidal Anti-inflammatory Agents, “NSAIDS,” such as Advil, Motrin and Aleve;
- Cold or allergy pills with pseudoephedrine or other decongestants which can raise blood pressure (be sure to read the label);
- Over the counter diet pills;
- Herbal supplements;
- Bactrim; and
- Iodinated contrast dyes used in CT scans.

If your kidney function is reduced, you should also not receive gadolinium, a contrast dye used for MRI studies.

### **CAN I EXERCISE?**

Certainly! Exercise will boost your energy levels, maintain your muscle mass and lower your blood pressure. It is advised to avoid contact sports that could aggravate the kidneys. Instead, try gentle, but effective activities such as walking, bicycling or swimming. Aim for 30 minutes a day, six times a week.

# LIVING WITH PKD

## WHAT ARE THE CHANCES THAT I WILL DEVELOP KIDNEY FAILURE?

Approximately 50% of people with PKD develop kidney failure or end-stage renal disease (ESRD), for which dialysis and transplantation are the only treatment options.

### SOME OF THE SYMPTOMS OF KIDNEY FAILURE ARE:

- Fatigue;
- Poor appetite, weight loss;
- Nausea/Vomiting;
- Trouble concentrating (in severe cases, confusion);
- Dry, itchy skin (especially if phosphate is high);
- Funny taste in your mouth – food tastes odd, metallic;
- Muscle cramps at night;
- Swelling in feet, ankles; and
- Mild to moderate depression.

### WHAT IS DIALYSIS?

Dialysis is a procedure that removes extra fluid, electrolytes and wastes when your kidneys are no longer able to do so effectively. There are two types of dialysis: hemodialysis and peritoneal dialysis. In hemodialysis, blood is circulated into an external filter, where wastes and toxins are removed before re-entering the body; in peritoneal dialysis, a fluid is introduced into the abdomen, where it absorbs wastes and is then removed.

### WHAT IS TRANSPLANTATION?

With kidney transplantation, a healthy kidney is placed in the lower abdomen and takes over the function of the failed kidneys. Transplantation is usually a better long-term treatment than dialysis. Healthy kidneys transplanted into PKD patients do not develop cysts.

If possible, blood transfusions should be avoided in order to prevent the development of antibodies which may prevent you from taking kidneys from certain donors. The optimal source of a kidney transplant is a close relative. However, relatives of patients with PKD may also have PKD, and screening and suitability as a transplant donor may reveal new diagnoses of PKD in people who didn't know that they were affected.

### DISCLAIMER

*The information in this brochure is for educational purposes only. For specific questions regarding your health care, please consult your nephrologist or health care team.*

# HOPE & SUPPORT



## **YOU ARE NOT ALONE!**

The PKD Foundation of Canada is the only organization, nation wide, fighting PKD through research and patient education. A few of the programs the PKD Foundation of Canada offers to provide hope and support include:

### **VOLUNTEER CHAPTERS:**

PKD Foundation of Canada Chapters across the country offer education, support and hope for patients and loved ones affected by PKD. By joining a chapter, you have the opportunity to connect with other PKD patients and families in your community and participate in a wide range of activities. PKD Foundation of Canada Chapters provide you with up to date educational seminars, local advocacy programs, opportunities for you to help promote PKD awareness and exciting and fun special events for your entire family.

### **NATIONAL PKD SYMPOSIUM:**

The PKD Foundation of Canada hosts a biennial PKD symposium, bringing together top PKD doctors and nutritionists from across the country to speak to you about current research, nutrition, transplantation, dialysis and emotional aspects of PKD.

The National PKD Symposium is the only educational event of its kind in Canada for patients and their loved ones.

### **WALK TO END PKD:**

Don't miss this opportunity to "Make a Cure Your Finish Line" and raise money for PKD research and education. The Walk to END PKD is the only nationally-run fundraising event aimed at finding a cure for PKD. The event is run almost entirely by dedicated volunteers from across Canada. Each September, you can step out and walk for a cure at an event near you.

### **GOVERNMENT ADVOCACY:**

The PKD Foundation of Canada's advocacy program makes it easy for patients and loved ones to stay up-to-date and get involved in important PKD issues in Ottawa, ON, and beyond. You can help end genetic discrimination and secure additional federal support of PKD research!

SUMMER  
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