



Live Kidney Donation: Medical Toolkit

CHAPTER • 7

Kidney donation for people at family risk of polycystic kidney disease

What is Polycystic Kidney Disease (PKD)?

Polycystic Kidney Disease (PKD) is a problem that causes many cysts (fluid-filled sacs) to form in your kidneys.

PKD runs in families. If your parents or siblings have PKD, there's a chance you may also have it.

PKD gets worse as you get older and can lower your kidney function and lead to kidney failure.

How will I know if PKD will stop me from donating?

If you have a family member with PKD, doctors will do tests during your donor evaluation to tell if you also have PKD.

Doctors may do:

- An ultrasound of your kidneys to look for cysts – doctors count the number of cysts and compare the number to your age to know if you have PKD
 - An MRI of your kidneys
 - Genetic testing by taking a small sample of your blood, skin, or other tissue to test your genes for PKD – doctors use this when they know the gene that caused PKD in your family member
- › If you have PKD, you won't be able to donate your kidney
- › If you are less than 40 years old and an MRI shows you have less than 5 cysts in your kidneys, doctors may let you donate

References

1. Huang, E., Samaniego-Picota, M., McCune, T., Melancon, J.K., Montgomery, R.A., Ugarte, R., Kraus, E., Womer, K., Rabb, H., and Watnick, T. 2009. DNA testing for live kidney donors at risk for autosomal dominant polycystic kidney disease. *Transplantation* 87:133-137.



What are symptoms of Polycystic Kidney Disease (PKD)?

Most people don't get symptoms until they are 30 to 40 years old.

Symptoms of PKD include:

- Back or side pain
- High blood pressure
- Larger belly size
- Blood in your urine
- Frequent bladder or kidney infections

Learn more about PKD at: <https://www.kidney.org/atoz/content/polycystic>

2. Chapman, et al. Autosomal-dominant polycystic kidney disease (ADPKD): executive summary from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference *Kidney Int.* 2015 Jul;88(1):17-27. doi: 10.1038/ki.2015.59. Epub 2015 Mar 18.

Note: This information is the opinion of the Living Donor Community of Practice (LDCOP) of the American Society of Transplantation. The LDCOP is a group of health care professionals and researchers who specialize in living kidney donation. The LDCOP's recommendations are meant to offer you helpful information, but you may find opinions from other groups or organizations that are helpful to you, too.