

Living well with ADPKD

If you just learned that you have autosomal dominant kidney disease (ADPKD), **here are next steps you can take.**

Find a nephrologist (kidney doctor) who you trust



You and your nephrologist are partners in your care. Nephrologists specialize in caring for kidney disease and other health problems caused by ADPKD. They should explain your disease and care plan in a way you can understand.

Talk with your nephrologist about their experience caring for patients who have ADPKD. Some nephrologists have more experience with ADPKD than others.

You have the right to get a second opinion.

You may consider a second opinion if your doctor has less experience with ADPKD or suggests a care plan and you want another doctor's opinion to decide if it is right for you.

You can also look for another doctor if your doctor does not include you in decisions about your care or does not have much experience with ADPKD. You can ask your current nephrologist, primary care provider or insurance company for names of other nephrologists or for a different referral.

For example, you could ask:

- "Can you describe your experience caring for patients who have ADPKD?"
- "I am thinking of getting a second opinion. Can you recommend someone you trust?"
- "Before we start this new care plan, I would like to get a second opinion. Can you help me with that?"

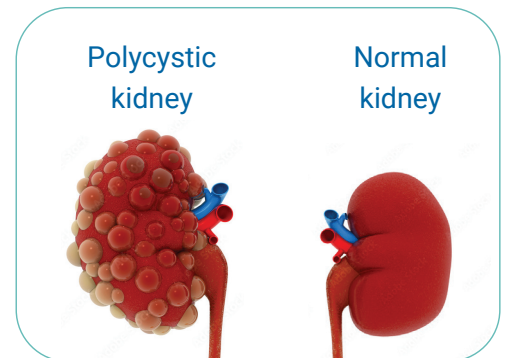
Work with your nephrologist to understand your risk (chance) of kidney failure

When you have ADPKD, the number and size of cysts in your kidneys will increase over time. This causes your kidneys to also grow larger in size. The cysts damage your kidneys and can lead to kidney failure, which means your kidneys stop working.

Talk with your nephrologist about the size of your kidneys.

This can predict the length of time it may take for kidney damage to progress to kidney failure.

Go to all of your appointments so your nephrologist can watch the size of your kidneys over time.



Follow your care plan

Your nephrologist will create a plan to manage your blood pressure, help your kidneys work longer and slow down damage to your kidneys. Follow the steps they give you, such as to:



Take all of your medicines as prescribed. Ask if you can take a medicine that can slow the progression of ADPKD to kidney failure.



Follow a kidney-friendly eating plan. A dietitian can help make a plan that works for you. Learn more at [Kitchen.KidneyFund.org](https://www.kitchenkidneyfund.org)



Be active for at least 30 minutes most days of the week.



Quit smoking or using tobacco.



Limit or avoid drinking alcohol. The healthy guidelines for drinking alcohol are:



For women:

One drink or less per day



For men:

Two drinks or less per day

Ask your doctor if it is safe for you to drink alcohol.

Find support

Living with ADPKD can be challenging in many ways. Learning you have a genetic disease with no cure can be worrying. Pain from growing or ruptured cysts, infections and kidney stones can make it hard to go about your daily routine. Swelling around your kidneys may change how your body looks in a way that makes you uncomfortable. You may also feel overwhelmed by making lifestyle changes and struggle with not being able to do things you once enjoyed.

The good news is you are not alone. There are people and resources that can help.



Talk with your doctor about your emotions.

Tell your doctor if you are feeling down, stressed, anxious, have negative thoughts or generally do not feel like yourself. They can connect you with a social worker to help you cope or mental health provider for therapy or counseling.



Join a support group.

Try an in-person or online support group with other people affected by ADPKD or other long-lasting diseases. This can be a welcoming place to talk about your experiences and feelings, and get advice and support.



Ask your family and friends for help.

Tell your family and friends about ADPKD and how you are feeling. This can help them understand what you are going through. They can also be part of the support system that encourages you to follow your care plan. Ask for help when you need it, such as a ride to a doctor visit or help with chores.



Get genetic counseling.

Genetic counselors can help you learn more about how ADPKD may affect your family and what actions your family members can take to understand their risk for ADPKD. They can also offer advice on what to consider if you are planning to start a family.



Take care of yourself.

Be patient with yourself and remember that even small steps add up.

- Learn more about ADPKD at KidneyFund.org/ADPKD
- Get involved with the PKD Foundation and find a PKD specialist near you at PKDcure.org