Living well with ADPKD

If you recently learned that you have autosomal dominant polycystic kidney disease, **here is what you can do next:**

1. Find a nephrologist (kidney doctor) who you trust

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.

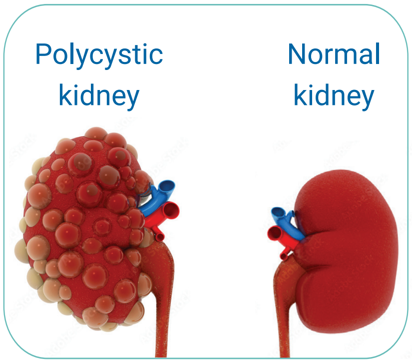
You have the right to get a second opinion.

Some nephrologists have more experience with ADPKD than others. If your doctor has less experience, you can seek out a second opinion. This can also be an option if your doctor is not including you in decision making. You can ask your nephrologist, primary care provider or insurance company for a different nephrologist.

Questions you can 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?"**

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



ADPKD causes cysts on your kidneys, which will grow in size and number overtime. This causes your kidneys to grow in size too. The cysts damage your kidneys and can lead to kidney failure.

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.

3. Follow your care plan

Your nephrologist will create a plan to manage your blood pressure, help your ADPKD to help slow damage to your kidneys and keep them working for longer.
Steps in your plan care may include:

Talk to your doctor about medicine options to slow the progression to kidney failure.

Follow a kidney-friendly eating plan and drink plenty of water. Food and water play an important role in managing ADPKD. A dietitian can help make an eating plan that works for you, and your kidney specialist can tell you how much daily water you should drink. Learn more at **Kitchen.KidneyFund.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:	For men:
One drink or less per day	Two drinks or less per day

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

4. Find support

Receiving an ADPKD diagnosis can be overwhelming. Pain from cysts, infections to your kidneys, and other changes can affect your daily routines and how you feel about your body.

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 mental health provider who can provide specific support.

Join a support group.

Try an in-person or online support group with other people affected by ADPKD or other chronic 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**

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Developed with support from Otsuka