



Talking With Your Family and Friends

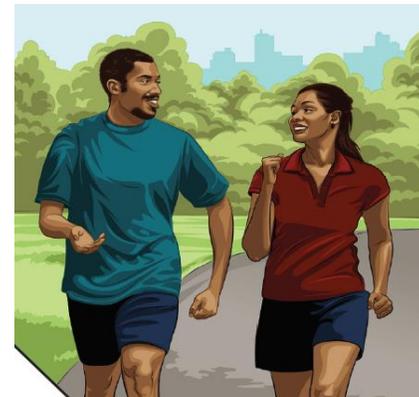
Talking about your ADPKD diagnosis and condition is your decision to make. You decide if, when, and to whom you share your story. If you decide to talk about it, do it in a way that feels most comfortable to you.

Talking with family members about ADPKD

Because ADPKD is genetic, meaning it runs in families, it can affect the family as a whole. This is one reason you may find it essential to talk with family about your diagnosis. In fact, many PKD experts suggest you share information about your condition, especially with adult family members. This gives them the chance to learn about what is going on with you, become educated about ADPKD, and possibly make informed choices about their own medical care.

Below are some important reasons for talking about your ADPKD diagnosis with family members:

- It gives you the chance to share how you are affected and learn how they are affected.
- Early diagnosis may mean better disease management by treating symptoms such as high blood pressure and making lifestyle changes to help protect kidney function.
- Early treatment may help manage disease-related complications.
- Early screening and diagnosis may make it possible to continue leading an active and productive life for longer.
- Genetic testing and counseling can be helpful when planning a family.
- Early diagnosis may lead to early screening of family members.
- Learning about ADPKD and having an open discussion about its implications may help families plan for potential future management options (eg, dialysis, transplant, organ donation).



Talking about ADPKD is a personal decision. If you decide to talk about it, do it in a way that you are comfortable and feels easiest to you.

Talking with friends about ADPKD

Friends can offer you support and an ear to listen when you want it. Again, tell them as much as you feel comfortable sharing. Keep in mind that many of them may not be familiar with your condition. Be prepared to educate your friends about ADPKD and CKD. And ask for help, when you need it — that's what friends are for.

Tips for talking with children and young people about ADPKD

You may have a child, regardless of age, who either has ADPKD or is at risk for having ADPKD. As a parent, sharing your experience and knowledge may help them be more familiar with ADPKD and less afraid. It may also help your child understand what is going on with you (or with other family members who are diagnosed). Consider the following tips if and when you choose to talk with your child about ADPKD:

- Bear in mind, **there is no single “right” approach**. You know your child and what may or may not be right for him/her.
- **Share your experiences** and knowledge to help children understand and feel less afraid.
- **Answer questions** as simply and honestly as possible.
- **Keep the conversation ongoing**; children often need information given to them more than once. They also may need time to process what you've told them and then want to come back to discuss or ask questions.
- **Explain to your child** the hereditary nature of the disease. For example, there was a 50 percent chance of him/her inheriting it and there's a 50 percent chance they could be passing it on to their own children.
- If your child has been diagnosed with ADPKD, **consider working with his/her healthcare team** about the right approach to talking about their condition, medical tests, and healthcare plan.

Communication can be an important part of coping with chronic diseases like ADPKD.

When you tell people close to you about your condition, it gives them the chance to offer you their support and love.

Questions? Concerns? Never hesitate to ask.

You have a right to know everything about your health and your care.