



At Risk for ADPKD?

A Guide for Talking About ADPKD

ADPKD, or autosomal dominant polycystic kidney disease, accounts for most cases of polycystic kidney disease (9 out of 10). Some people with ADPKD are at risk for accelerated disease progression.

You should talk to your doctor if a member of your family has or has had ADPKD — or if you think you have symptoms of the disease. Use this discussion guide to help start the conversation.

Here are some examples of questions you may want to ask your care team. Feel free to bring this sheet to your next appointment.

I have a parent who was diagnosed with ADPKD. Are there symptoms associated with ADPKD that I should be aware of?

I've been having a lot of pain in my back and sides. Could it be a symptom of ADPKD?

I get a lot of urinary tract infections. Could they be warning signs of ADPKD?

If there's blood or protein in my urine, should I be concerned about ADPKD?

How would an ADPKD diagnosis change my daily activities?

If I have family members who have had kidney failure, should I be screened for ADPKD?

What type of screening would I get?

Would I need to have more than one type of screening?

How often would I need to get screened?

The sooner you know how fast your disease is progressing, the sooner you and your healthcare provider can decide on a treatment plan.

Questions? Concerns? Never hesitate to ask.

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