



NephU™

Improving Awareness
& Patient Outcomes

Working With Your Healthcare Provider to Help Manage ADPKD

A Resource for Patients

ADPKD, or autosomal dominant polycystic kidney disease, accounts for most cases of polycystic kidney disease (9 out of 10). ADPKD may progress quickly for some people. That's why it's so important to talk with your doctor.

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Decision making when you have ADPKD

Living with a chronic kidney disease like ADPKD means you face decisions throughout your lifetime as your illness progresses. Your healthcare providers can help you make these decisions. Shared decision making is a process in which you work with your doctors to make treatment and care plan decisions together. Decisions are reached by taking into account evidence-based treatment options and your treatment goals, values, and lifestyle preferences.

Renal associations in the United States support and encourage the use of shared decision making as a patient-centered approach to reaching decisions in chronic kidney disease.

The goal of shared decision making is to arrive at a quality decision that is informed by:

- Your goals and values
- A broad range of support

Shared decision making can be used when making any decision important to your health. For example, you can use it to make simple decisions like the right exercise routine to fit your needs or for harder decisions like which medicines are right for you to manage symptoms. You may find engaging in shared decision making with your healthcare team can help support you and your management plan through the stages of ADPKD.



As your condition progresses, there may be different decisions you need to make with your healthcare providers about management options and treatments.

Some examples of key decision areas include:

- Genetic testing/counseling
- Diagnosis options
- Clinical trials
- Family planning
- Lifestyle modifications
- Symptom management
 - Hypertension
 - Pain
- Dialysis*
- Transplant*

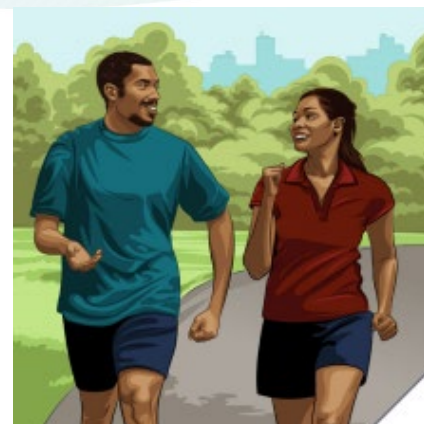
*Decisions occurring later in the disease progression.

Setting Goals

Goal setting is one central part of the shared decision making process. It can also be an important step in managing CKD.

Goal setting can help:

- **Direct** you toward changes you want to make
- **Point** you in a positive direction
- **Make** it easier to feel better
- **Support** self-management
- **Build** self-confidence



Tips for goal setting

- Set clear, realistic, and manageable goals
- Focus on one goal at a time
- Start with a small goal and then move onto a larger one
- Break goals down step by step
- Don't give up — keep trying until you find an approach that works for you

Consider what area(s) you may want or need to change and set goals in when managing CKD:

- Diet
- Exercise
- Medicines
- Relationships
- Symptom management options
- Occupational activities
- Activities you enjoy in your spare time

Shared decision making and goal setting can help you and your healthcare providers decide on management options that are right for you as you deal with symptoms of your ADPKD.

Management options to discuss with your doctor

- Eat a heart-healthy diet with fruits, vegetables, antioxidants, and high-fiber carbs that are low in sodium.
- Exercise regularly to improve blood pressure, sleep, heart health, bone mass, and more.
- Drink lots of water to avoid dehydration.
- Take medications as directed by your doctor and check with your healthcare provider before you make a change.
- Pay attention to your body so you can respond quickly and correctly to any issues.
- Keep all your appointments for scheduled checkups and routine testing.



Treatment options to discuss with your doctor

- ✓ Medication to manage ADPKD
- ✓ Medication to control hypertension
- ✓ Medication or surgery to reduce pain
- ✓ Symptom control and management
- ✓ Dialysis*
- ✓ Kidney transplant*

*Decisions occurring later in the disease progression.

**It is important to
keep your doctor
informed of your
symptoms.**

How will ADPKD change things?

What type of screening should I get? And how often?

How does ADPKD affect my other organs?

Are there any complications I need to be aware of?

What symptoms can I expect to experience over time?

What can I do to help reduce symptoms?

What are my treatment options?

Are there any medications that I should take?

What side effects will I experience from my medications?

What should I do if I notice new symptoms or symptoms getting worse?

I have ADPKD. Is it certain that my children will have it?

Who else in my family should be screened?

Additional questions:

Questions? Concerns?

Never hesitate to ask. You have a right to know everything about your health and your care.

If you have any questions or concerns about your condition or your care, ask your doctor or a member of your treatment team right away. They are there to help you.