Kidney Connections
Real Lives, Real Solutions in ADPKD: Living Better With ADPKD

My goals for living better with ADPKD

Short-term goals

Long-term goals

What's something important to me that my health care provider should know?

What are some things I can do now to take care of my kidney health?

Questions I want to ask my health care provider about ADPKD and treatment

Notes and instructions from my health care provider

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What is ADPKD?

- ADPKD stands for autosomal dominant polycystic kidney disease
- It is a genetic condition that causes fluid-filled cysts to grow in the kidneys
- As the cysts grow, the kidneys are less able to filter waste from the blood
- ADPKD can lead to kidney pain, high blood pressure, and kidney failure
- ADPKD can also cause cysts in the liver and other organs, but these do not usually lead to major health problems

What are the goals of treatment for ADPKD?

- Slow down cyst growth and kidney damage (top goal)
- Delay the need for kidney dialysis or kidney transplant
- Control blood pressure to protect the kidneys
- Prevent infections and manage pain
- Support overall health with a healthy diet, regular exercise, and no smoking or excessive alcohol
- Aim for a good quality of life

What are treatment options for ADPKD?

- Ask your health care provider about your options
- Tolvaptan is the only medication approved by the FDA to slow kidney function decline in adults with ADPKD who are at risk of rapidly progressive disease. (JYNARQUE® is the brand name of tolvaptan.)
- Tolvaptan works by blocking vasopressin, a hormone that causes cyst growth
- Clinical studies showed that tolvaptan treatment can slow kidney growth and loss of kidney function
- Other medications for ADPKD are now being tested in clinical trials

What can I expect if I take tolvaptan?

- Treatment plans should fit the person's needs—not everyone's plan will be the same
- Your health care provider will tell you the dose of tolvaptan, when to take the medication, and how to manage possible side effects
- Tolvaptan causes your body to lose more water through urination—this is how the medication works to slow kidney disease
- As a result, you may feel thirsty and need to urinate more often during the day and night. Many people find that these symptoms improve over time, so hang in there!
- Most people adapt to the changes in thirst and urination within days to months

Tips for managing thirst and frequent urination on tolvaptan

- Drink frequently and spread out your fluid intake during the day and night
- Choose plain water—it is the best way to replace fluid losses
- Avoid drinks with sugar or fat, and limit caffeine and alcohol

- Add citrus to plain water, or try sparkling water, if you need a change of pace
- Take a water bottle with you, especially if you leave the house
- Plan ahead for bathroom breaks, especially for work or travel
- Eat a larger lunch and a lighter dinner to cut down on urination at night
- Limit salty and high-protein foods that can increase thirst, especially later in the day
- Know the signs of dehydration: These may include thirst, dry mouth, dark-yellow urine, feeling dizzy or light-headed, headache, or tiredness; talk to your health care provider and have a plan to manage dehydration
- Know when dehydration is more likely to happen: For example, warm weather, exercise, fever, diarrhea, vomiting, or having limited access to water can put you at risk for dehydration; talk to your health care provider and have a plan to manage those situations
- Call your health care provider if you have trouble with thirst, urination, or dehydration, or if you have any questions about what to do

Liver safety monitoring on tolvaptan

- Tell your health care provider if you have a history of liver problems
- Tolvaptan can cause serious liver damage, so people taking this medication must be part of a special "REMS" program to monitor liver function regularly
- Your health care provider or pharmacist will tell you about the REMS program
- A simple blood test is needed to monitor liver function: blood is drawn 2 weeks and 4 weeks after starting the medication, then every month for the first 18 months of treatment, and every 3 months after that
- Call your health care provider if you have yellow skin, dark-colored urine, or abdominal pain, which can be signs of liver damage

Where can I learn more about ADPKD?

- Make an appointment to talk with your health care provider
- PKD Foundation
  - https://pkdcure.org
- National Kidney Foundation
  - https://www.kidney.org

References

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