

Tolvaptan Take-Home Tips

Are you starting tolvaptan to treat autosomal dominant polycystic kidney disease (ADPKD)? Tolvaptan can help slow the growth of kidney cysts, but it requires careful monitoring and some changes to your daily routine. This tip sheet explains everything you need to know to take the medicine safely, stay on track with labs and follow-up care, and manage side effects.

LAB WORK IS CRITICAL – NO LABS, NO MEDICINE

To safely take tolvaptan, regular blood tests are required:

- » Every two weeks for the first month
- » Once a month for the next 17 months
- » Every three months after that while on the medicine

FOLLOW-UP CARE

- » Your nephrologist will decide how often you need to come in for follow-up appointments.
- » You must have at least one visit per year to stay on tolvaptan.
- » Call your doctor:
 - » When your medicine arrives
 - » One week after starting tolvaptan to give an update
- » Typically, your nephrologist or care team will call you after reviewing your labs.

IMPORTANT REMINDERS

- » Morning urine tests must be done before your morning dose.
- » If you do labs outside of your nephrology clinic, be sure to send them to your nephrology clinic.
- » Keep access to your lab results in case your nephrologist needs a copy.
- » If your labs aren't received on time, your medicine will be put on hold.

WHERE THE MEDICINE COMES FROM

Tolvaptan can be shipped from the following REMS-certified pharmacies listed below. More pharmacies may be added in the future.

- » **Commercial Insurance:** AllianceRx, Optum, and PantherxRare
- » **Patient Assistance Program:** Eversana

WHAT IS REMS CERTIFICATION?

- » REMS (Risk Evaluation and Mitigation Strategy) is a safety program from the FDA. REMS certification means a doctor, nurse, or pharmacy is trained and follows special rules to safely provide certain high-risk medicines.

SIDE EFFECTS – WHAT TO EXPECT

Most side effects typically get better after 3–6 months:

- » Peeing, or urinating, more often
 - » **Daytime urination:** expect every 1.5–2 hours while taking tolvaptan
 - » **Nighttime urination:** expect two to three times per night while taking tolvaptan
- » Thirst, dry mouth, tiredness
- » Dehydration symptoms: dizziness, low energy, low blood pressure
- » Constipation

Call your nephrologist right away if you're leaking urine or urinating more than normal.

WATCH FOR SYMPTOMS OF SERIOUS LIVER PROBLEMS

STOP THE TOLVAPTAN AND CALL YOUR NEPHROLOGIST RIGHT AWAY IF YOU HAVE:

- » Pain in the upper right belly
- » Yellow skin or white part of the eye (jaundice)
- » Vomiting, no appetite
- » Rash, fever, itchy skin
- » Dark urine
- » Feeling very tired

BLOOD PRESSURE AND SODIUM

- » **Goal blood pressure:**
 - » Under 110/75 if age 18–50 and kidney function (eGFR) is above 60
 - » Otherwise under 130/85
- » **Sodium recommendation:** 2,300–3,000 mg/day

DRINKING WATER

- » Drink **5–6 liters** (about 1.3–1.5 gallons) a day, or enough to maintain adequate hydration and good sodium levels
- » **Best option:** plain water
- » You can add lemon, fruit slices or use sugar-free drink mixes like Crystal Light. Limit drinking fluids with calories.
- » If your tolvaptan is paused or stopped, **only drink when you feel thirsty. Do not drink more fluids than you need.**

FOOD, ALCOHOL, AND TOLVAPTAN TIPS

- » **No grapefruit:** it can interfere with tolvaptan
- » Let your doctor know if you start any **new medications or supplements**
- » **Avoid alcohol:** it can raise your liver function tests
- » If you're on **antibiotics**, pause tolvaptan and check in with your doctor

WHEN TO PAUSE TOLVAPTAN

- » If you have vomiting or diarrhea, wait to take tolvaptan until you can eat and drink normally again.
- » If you're having surgery or a medical procedure, stop taking tolvaptan a few days before. Start again once you are eating and drinking normally.
- » If you're in the hospital
- » If you're traveling and don't have access to clean drinking water

TRAVELING FOR WORK? You'll need a plan to keep taking the tolvaptan regularly.

WORKING NIGHT SHIFTS? Ask your doctor about taking the smaller dose in the morning and the larger dose in the afternoon.

PREGNANCY AND BIRTH CONTROL

- » If you want to become pregnant, please call your doctor to stop the tolvaptan
- » If you become pregnant while taking tolvaptan, stop tolvaptan and call your doctor
- » Birth control is recommended while taking tolvaptan

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