

Taking tolvaptan for ADPKD (Kidney Disease)

Kidney services

Last reviewed: November 2025

Next review: November 2028

Information for Patients

Leaflet number: 425 Version: 3

Introduction

This leaflet has information about **tolvaptan** for the treatment of **autosomal dominant polycystic kidney disease (ADPKD)**.

This information is also available in a short video format. Use your smart phone to scan this QR code to watch the video or visit this link:

www.youtube.com/watch?v=lpWwOsUTSq0



What is tolvaptan and what does it do?

- In ADPKD, small fluid-filled cysts grow in the kidney. This puts pressure on the tissues around it. It reduces kidney function and could lead to kidney failure.
- Tolvaptan is a medication used to **slow the progression of ADPKD** by reducing the growth of kidney cysts.
- It works by blocking a hormone called vasopressin (also called anti-diuretic hormone or ADH). This helps regulate water balance in the body.
- By blocking ADH, tolvaptan helps the body make more urine (pee). This reduces fluid buildup in kidney cysts and slows kidney damage.
- Tolvaptan does **not affect liver cysts**.

Who can take tolvaptan?

Tolvaptan is available for certain NHS patients who meet **both** of the following criteria:

- have rapidly progressing ADPKD
- have chronic kidney disease stage 2 or 3 at the start of treatment

Speak to your doctor if you are not sure if tolvaptan is right for you.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

How long does tolvaptan take to work?

People notice that they feel thirsty and make more urine as soon as they start taking tolvaptan. The effects of tolvaptan are seen in the long run (over years). People may still develop cysts and their kidneys may eventually fail. Tolvaptan can slow the speed that this happens. This means that kidneys may work for longer and delay needing dialysis or a transplant.

What will I have to do if I take tolvaptan?

- Attend regular clinic appointments.
- Have routine blood tests as scheduled.
- Get a supply of tolvaptan only from the hospital (not from your GP).
- You may be asked to give consent to join the **Rare Disease Registry (RaDaR)** and **Patients Know Best**, which helps improve understanding of how effective Tolvaptan is in treating ADPKD.

How do I take tolvaptan tablets?

Tolvaptan is usually taken 2 times a day. When you start treatment you will usually take:

- 45mg in the **morning** when you wake up. This should be 30 minutes before breakfast.
- 15mg **8 hours after** the first dose, with or without food.

If your body tolerates it well, we will increase your dose. Tolvaptan is most effective at the highest dose. Some people are unable to manage the effects of tolvaptan at this dose so they take a smaller dose. Tolvaptan is still effective at the lower doses.

What if I forget to take tolvaptan?

If you forget to take a dose of tolvaptan you should just take your next dose as normal. **You must not take 2 doses to make up for forgetting.**

Pregnancy and breastfeeding

Women must not become pregnant if they take tolvaptan. This is because it may harm the unborn baby. Women of childbearing age must use effective method of contraception for:

- at least 4 weeks before starting treatment with tolvaptan,
- during treatment with tolvaptan,
- at least 4 more weeks after stopping tolvaptan.

Tell your kidney doctor if you are planning to become pregnant. They will give you advice to reduce the risk to you and your unborn baby. If you are or think you may be pregnant while taking tolvaptan you must stop taking it right away and tell your doctor, nurse or pharmacist.

You must not breastfeed while taking tolvaptan.

What are the side effects of taking tolvaptan?

When you start taking tolvaptan, it may cause your body to make more urine. This can make you thirsty and make you urinate (pee) more often. You may wake up at night to urinate or feel the need to urinate often during the day. To help manage these effects, you must drink enough water to replace the extra fluid your body is losing through urine.

To prevent dehydration and protect your kidneys, you must:

- Drink plenty of fluids throughout the day, even if you are not thirsty.
- Drink 1 to 2 glasses of fluid before bed.
- If you pass urine during the night, drink again.

If you have any condition that could make you dehydrated, for example, being sick (vomiting) or having diarrhoea, you should drink more fluids. Follow the advice in this leaflet in the section called 'sick day plan'.

Rarely, tolvaptan can damage the liver. This often can happen within a few months of starting tolvaptan. In most people, this gets better when tolvaptan is stopped. There is a small chance that tolvaptan can cause permanent and serious damage to the liver.

Signs and symptoms of liver damage include dark urine, yellowing of the skin or eyes (jaundice), and itching. Please contact your kidney doctor or GP if you think you have liver problems.

To reduce the chances of liver damage happening you will have blood tests called Liver Function Tests (LFTs). You will have this test:

- Before starting treatment with tolvaptan.
- 1 week after starting tolvaptan.
- Every month for the first 18 months of treatment.
- Every 3 months thereafter for as long as you take tolvaptan.

It is very important that you have your blood tests when your doctor or pharmacist asks you. **If you do not have your blood tests, they will not be able to continue prescribing tolvaptan for you.**

If blood tests show that there are signs of liver damage we may recommend stopping tolvaptan for a short period. You may be able to restart tolvaptan when the liver tests return to normal.

Rarely, blood tests show severe liver damage or the liver function tests become abnormal again after re-starting tolvaptan. If this happens you may need to stop taking tolvaptan permanently.

Sick day plan

Being sick (vomiting), diarrhoea and fever (high temperature, sweats, shaking) can cause dehydration. This may cause damage to the kidneys.

If you are sick or have diarrhoea once, drinking more fluids will stop you from dehydration. If you have diarrhoea or vomiting 2 times or more, stop taking tolvaptan until you have recovered fully. Make sure you drink plenty of fluid when you are unwell. Start taking tolvaptan again once you have been well for at least 24 hours with no diarrhoea or vomiting.

Taking a break from tolvaptan

Sometimes you may need to take a break or 'holiday' from taking tolvaptan. For example, you might not wish to take your tolvaptan if you are going on a long car journey or if your access to toilets are limited. If you keep taking a 'holiday' you may not get the full benefit of tolvaptan. Talk to your kidney doctor or pharmacist if you are taking 'drug holidays' or missing doses regularly.

Can certain foods and medicines affect my tolvaptan levels?

Some medicines including herbal medicines, supplements and medicines that you buy over the counter can interact with tolvaptan. It can cause increased side effects or make tolvaptan less effective.

Some examples of medicines that affect the level of tolvaptan in the body are:

- some antibiotics (such as Clarithromycin, Erythromycin, Ciprofloxacin),
- anti-fungals (such as Fluconazole ketoconazole),
- anti-epileptics (such as Carbamazepine, Phenytoin),
- herbal medicines (such as St John's Wort),
- some blood pressure tablets (such as Verapamil, Diltiazem).

Some foods can also interfere with tolvaptan. Do not eat grapefruit, grapefruit juice and products made with Seville oranges while taking tolvaptan.

Always check with your kidney doctor or pharmacist before you start any new medicines, including herbal, medicines bought from the health shop or over the counter.

How do I get my tolvaptan?

When you first start tolvaptan you will get the medicine delivered to your home. This is called a home delivery. If you prefer, your tolvaptan can be delivered to another address. For example: your local pharmacy, work, a neighbour or relative's home.

You can also collect your Tolvaptan from a TrustMed Pharmacy (there is one in each Leicester Hospital). This service is free.

Your GP will not be able to give you your tolvaptan. You have to get them from the hospital.

How does home delivery work?

The Kidney Pharmacy Team will create a prescription for your Tolvaptan. They forward this to your Kidney Consultant. The medicine will be sent from the TrustMed Pharmacy at the Leicester General Hospital to the Charnwood logistics drivers. This process takes 7 to 10 days.

How do I register for home delivery?

To register for the prescription service of your tolvaptan, you need to speak to a member of the Kidney Pharmacy Team. They will normally contact you when they have been told you will be started on tolvaptan by your Kidney consultant.

The registration process has 3 steps:

1. Information and questions:

A member of the Kidney Pharmacy Team will tell you about home delivery and answer any questions you have.

2. Registration form:

You will need to complete a registration form. We will need the following details:

Your name, home address, delivery address (if different from your home address), date of birth, hospital number, phone number and your GP details.

You will need to sign the registration form. This means that you give consent to join the prescription service for your tolvaptan. The form will also need to be signed by a member of the Kidney Pharmacy Team.

3. Education session:

A member of the kidney pharmacy team will then send you a link to a video about tolvaptan. They will arrange a date with you to go through the medication and answer any questions you may have about the medication.

Who dispenses my tolvaptan?

Your prescriptions will be prepared by the Kidney Pharmacy Team and dispensed by TrustMed Pharmacy (outpatient pharmacy).

How will my tolvaptan be delivered?

Charnwood logistics drivers will deliver your tolvaptan to your chosen address. Deliveries are made during working hours from Monday to Friday. You will need to sign a form as proof that your medicine has been delivered. If there is no one available at the delivery address when your tolvaptan is delivered, the drivers will leave a card with a number to call to rearrange a different delivery day.

How do I get more supplies of my medicines?

You need to contact the Kidney Pharmacy Team when you need a supply of your tolvaptan. You will get a months supply of tolvaptan each time for the first 18 months. You must order your repeat prescription when you have **at least 2 weeks left** of your tolvaptan.

To order your repeat prescription you can:

Ring the Kidney Pharmacy Team on 0116 258 8177.

When we speak to you we will ask for your personal details and confirm the delivery address. We will also check which dose of tolvaptan you are taking. If you get through to an answerphone message, leave your name and contact telephone number and the Kidney Pharmacy Team will ring you back.

Or email a request for your tolvaptan to uhl-tr.kidneypharmacyteam@nhs.net



All information sent through to the University Hospitals of Leicester through your personal email is not automatically secured. All the information will be handled in a confidential way by the Kidney Pharmacy Team staff. The Kidney Pharmacy Team will call you to confirm details.

Remember that getting your tolvaptan ready can take 7 days in total. This is why it is so important that you call the Kidney Pharmacy Team at least 2 weeks before you run out of tolvaptan.

If you run out or only have a few days of medication left, the Kidney Pharmacy Team will try to organise an urgent delivery. This may not always be possible. If you give us less than 48 hours (2 days) notice you will need to come to collect your medicines from TrustMed Pharmacy at the Leicester General Hospital.

What do I do if my delivery has not arrived?

Your tolvaptan should arrive on the agreed delivery date or week. If they do not arrive or if you have very few days left of tolvaptan, call the Kidney Pharmacy Team right away. They will be able to find out when your tolvaptan will be delivered to you.

If you would like your tolvaptan to be delivered on a specific date, tell the Kidney Pharmacy Team. They will try to organise this for you.

More information

For more information about ADPKD and tolvaptan please visit these websites:

- **PKD Charity:** <http://pkdcharity.org.uk/>
- **Kidney Care UK:** <https://kidneycareuk.org/kidney-disease-information/kidney-conditions/autosomal-dominant-polycystic-kidney-disease-adpkd/>
- **NHS:** www.nhs.uk/conditions/autosomal-dominant-polycystic-kidney-disease-adpkd/

Contact details

Kidney pharmacy team call on **0116 258 8177**, email: uhl-tr.kidneypharmacyteam@nhs.net

Opening hours: Monday to Friday 9am to 5pm

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
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Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as Easy Read or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk