

Patient Information

Tolvaptan for Adult Polycystic Kidney Disease (ADPKD)

Lister Renal Department



What is tolvaptan?

Tolvaptan is a drug specifically for the treatment of adult polycystic kidney disease (ADPKD). It has been approved for use in the NHS by The National Institute of Health and Care Excellence (NICE) for some people with ADPKD.

How does tolvaptan work?

Tolvaptan is a medication that affects how the kidneys control the concentration of urine. Taking tolvaptan will cause you to produce a larger amount of more dilute urine.

Tolvaptan has been shown to slow down the growth of kidney cysts in some people with ADPKD when it is taken for a long time (several years). This may help to protect the function of your kidneys and delay the need for a kidney transplant or dialysis. Your kidney function will continue to decline, but at a slower rate.

Who can take tolvaptan?

Tolvaptan is available to NHS patients who have rapidly progressing ADPKD and mild chronic kidney disease (known as CKD stage 2 and 3). Mild chronic kidney disease means that you have less than 90% kidney function but more than 30% kidney function. Rapidly progressing means that you are losing about 5% of your kidney function each year.

How long does tolvaptan take to work?

You will notice the effects of taking tolvaptan immediately. These include an increased thirst and urine production. However, the effects on cyst growth and kidney failure will be much slower and only become apparent with long-term treatment (over years).

It is important to understand that tolvaptan will not stop the progression of your ADPKD. You may still develop cysts and eventually develop kidney failure. However, the aim of treatment with tolvaptan is to slow the speed at which this happens.

Before starting tolvaptan

Because this is an expensive medication, before you can start tolvaptan, we need to register you with the Integrated Care System (ICS) to get funding. You may get a letter from them.

What will I have to do if I take tolvaptan?

You will need to be seen more frequently than you are at the moment. You may need to travel to the Lister Hospital for your appointments every month for the first 18 months of treatment. This is because you will need to be closely monitored whilst receiving your tolvaptan treatment, and the medication can only be supplied from the Lister Hospital pharmacy. This can be collected or delivered to you.

Tolvaptan can cause inflammation of the liver. Usually this occurs within 3-14 months of starting tolvaptan if it is going to happen, and resolves on stopping treatment. However, there is a small risk that tolvaptan could cause permanent and potentially life-threatening damage to your liver.

To reduce the risk of this happening we must monitor you by taking a blood test called a liver function test (LFTs):

- Before starting treatment
- Every month for the first 18 months
- Every 3 months thereafter for as long as you take tolvaptan

If your blood tests show that there are signs of liver inflammation we may recommend that you stop taking tolvaptan for a short period until your blood tests have returned to normal, after which it may be safe to re-start treatment.

National Database

In order to help us to continue to understand ADPKD, we will ask you to consider joining the Rare Renal Registry (RaDaR).

RaDaR is a national database which collects information about people with ADPKD - Website: <http://rarerenal.org/radar-registry/>

How to take tolvaptan tablets

Tolvaptan comes as tablets and is taken twice a day. A larger dose is taken in the morning and a smaller dose 8 hours later in the afternoon.

When you start treatment you will usually be advised to take:

- 45mg in the morning upon waking, 30 mins before breakfast
- 15mg eight hours after the first dose, with or without food

After 4 weeks, if you are managing the effects of tolvaptan well, you will be advised to increase the dose to 60mg and 30mg.

After another 4 weeks, if you are still managing, you will be advised to increase the dose again to 90mg and 30mg.

Tolvaptan will be increased to the maximum tolerated dose.

Does tolvaptan have any side effects?

Tolvaptan will make you pass urine more often, so you will feel more thirsty than usual. You may need to pass urine as often as every hour and you will most likely need to pass urine during the night. You will need to drink plenty of water to prevent from becoming dehydrated, usually 4-6 litres each day. It is advised to drink 1-2 glasses of water before going to bed even if you don't feel thirsty, and more in the night if you pass urine.

Tolvaptan can also cause liver problems so regular blood tests are essential. Tolvaptan can cause an increased risk of skin cancers and glaucoma.

Pregnancy and breastfeeding

You should not take tolvaptan if you are trying to get pregnant or during pregnancy, as it may damage your unborn baby. Tolvaptan should not be used whilst breastfeeding. You must use reliable contraception for at least 4 weeks before starting tolvaptan, during treatment and for 4 weeks afterwards.

What should I do if I become unwell?

If you have more than two episodes of vomiting or diarrhoea you

should stop your tolvaptan tablets until your symptoms have settled. Continue to drink plenty of clear fluids and restart your tolvaptan once you have had no vomiting or diarrhoea for 24 hours. This will prevent you from getting dehydrated.

Hot weather

In the event of any severely hot weather, if you can't adequately rehydrate, stop tolvaptan until the weather is cooler. This will avoid you becoming dehydrated.

Drug holidays

Occasionally you may need to take a 'holiday' from tolvaptan. For example, if you were going to take a long car journey, where access to toilets could be difficult, you may not take your tolvaptan on that day. If you are going on a holiday to a hot place it would be advisable to withhold your tolvaptan whilst you are away and restart when you get home. If you find you are taking drug holidays or missing doses every week, then tolvaptan is probably not for you, you won't be getting the full benefit.

Interactions with food and other medications

Other medications may interact with tolvaptan and cause increased side effects or make tolvaptan less effective. This includes herbal medicines, supplements and medicines that you can buy over the counter.

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

- Some antibiotics (such as clarithromycin, erythromycin and ciprofloxacin)
- Anti-fungals (such as fluconazole)
- Blood pressure tablets (such as diltiazem)
- Herbal medicines (such as St John's Wort)
- Some foods (such as grapefruit or Seville oranges)

This is not a full list. Please speak to your doctor or pharmacist about your medications.

Patient view

This is individualised online information which is available to you to:

- find out your latest blood results
- read your letters from the renal unit

To find out more ask for a leaflet or visit www.patientview.org

Further information

Please also read the leaflet inside your medication box for more information about Tolvaptan.

Questions

Please speak to one of the renal team if you have any questions or concerns about tolvaptan or about any of the information in this leaflet.

Please use this space to write down any questions you may like to ask:

Contact Telephone Numbers

Renal Pharmacy Team

☎ 01438 284677

or e-mail: renalpharmacists.enh-tr@nhs.net

Dr Vilar's secretary

☎ 01438 284230

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