

# Tolvaptan for the treatment of adult polycystic kidney disease (ADPKD)

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**This leaflet will explain what Tolvaptan is, what medical condition it is used for and how it should be used. It provides important safety information and helps you to understand potential side effects of Tolvaptan and what to do if they occur.**

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## What is Tolvaptan?

Tolvaptan is a medicine used to treat adult polycystic kidney disease (ADPKD). ADPKD is a genetic condition that causes cysts to grow in the kidneys which interfere with their normal functioning, possibly leading to kidney failure.

## Who is likely to benefit from Tolvaptan?

Your renal doctor may recommend Tolvaptan if your ADPKD is at higher risk of leading to kidney failure, taking into consideration your family history, kidney function and kidney size. Generally, Tolvaptan is useful in patients with worsening kidney function (stage 2 and 3 chronic kidney disease), or with large kidneys (greater than 16.5cm in length).

Tolvaptan is not recommended for children under 18 years and adult over the age of 55.

## How does Tolvaptan work and what are its benefits?

ADPKD cannot be cured; however, it is possible to slow the onset of kidney failure through medication.

Tolvaptan blocks the effects of the hormone vasopressin. When thirsty, the brain uses vasopressin to tell the kidneys to hold onto water. Unfortunately, vasopressin also tells the cysts to grow. Hence Tolvaptan tells the kidneys to release water, increasing urination (peeing) but slows the growth of cysts.

Tolvaptan has also been shown to reduce kidney pain.

## 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. Studies have shown that for each four years of taking Tolvaptan, dialysis can be delayed by one year.

## How to take Tolvaptan

Tolvaptan comes as tablets and is taken twice a day in two different doses. The higher dose should be taken in the morning when you wake up, at least 30 minutes before breakfast. The lower dose is taken eight hours later with or without food. You will start on a low overall dose and this will be increased on a monthly basis. Swallow the tablets without chewing, with a glass of water.

## Does Tolvaptan have any side effects?

Due to its mode of action, you will feel more thirsty than usual and pass urine more often. It is important that you drink a large volume of water daily. Start by drinking at least three litres a day. You may need to pass urine as often as every hour and you will most likely need to pass urine during the night.

Tolvaptan can cause serious liver damage in some patients. This is reversible when treatment is stopped. Hence it is **very important that you have a blood test every month for the first 18 months of treatment**. After that, it will be every three months until you stop treatment.

Tolvaptan also increases uric acid level in the blood. This may then lead to gout (a type of arthritis that causes sudden, severe joint pain). Your doctor may prescribe another tablet called Allopurinol to prevent gout.

## Does Tolvaptan interact with any food or medication?

Avoid grapefruit juice and St John's Wort. Avoid drinking large quantities of alcohol, as it is very dehydrating.

Before you start Tolvaptan, your doctor or pharmacist will check what other medication you are taking to ensure that they are safe with Tolvaptan.

Whenever any doctor or dentist wants to start a new medication while you are on treatment, you should remind them that you are taking Tolvaptan. Alternatively, contact the ADPKD clinic to check if the new medication is safe with Tolvaptan.

## What should I do if I become unwell?

If you have more than two episodes of vomiting or diarrhoea, stop taking your Tolvaptan tablets. Continue to drink plenty of water. Restart the Tolvaptan tablets once you have no more vomiting or diarrhoea for 24 hours.

## What should I do if I forget to take Tolvaptan?

Take the next dose as normal. **Do not take a double dose** to make up for forgetting.

Occasionally, you may need to take a "holiday" from Tolvaptan. For example, if you are going to take a long car journey, where access to toilet facilities might be limited, you might not wish to take your Tolvaptan that day. However, do not 'miss' a dose more than once a month.

If you find you are taking drug holidays or missing doses every week, Tolvaptan is probably not right for you, as you won't be getting the full benefit of taking it.

## **Pregnancy and breastfeeding**

**You should not take Tolvaptan if you are trying to become pregnant or during pregnancy, as it may damage your unborn baby. Tolvaptan should also not be used while breastfeeding.**

If you are a woman and aged between 12 to 45, you must use a reliable and effective method of contraception for at least four weeks before starting treatment with Tolvaptan, during treatment with Tolvaptan, and for at least a further four weeks after stopping Tolvaptan. If you are or think you may be pregnant while taking Tolvaptan, you must **stop taking it immediately** and tell your doctor or pharmacist.

We will discuss with you the most suitable form of contraception to use. This is because the use of some oestrogen-containing contraceptives may increase the growth and development of cysts in the liver.

You must tell us if you are planning a pregnancy, so that we can advise you what steps to take to minimise the risk to you and your unborn baby.

## **How to contact us**

Renal Department, Royal Berkshire Hospital (Monday to Friday, 8am to 6pm)

Tel: 0118 322 1889, Email: (non-urgent queries): [apkd@royalberkshire.nhs.uk](mailto:apkd@royalberkshire.nhs.uk)

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**Please ask if you need this information in another language or format.**

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