

Oxford Kidney Unit

Tolvaptan (Jinarc[®]) for Adult Polycystic Kidney Disease (ADPKD)

Information for patients



What is tolvaptan?

Tolvaptan (Jinarc[®]) is the first drug specifically for the treatment of adult polycystic kidney disease (ADPKD). It has recently been approved for use in the NHS by the National Institute of Health and Care Excellence (NICE) for some people with ADPKD. The information in this leaflet will help you decide if this treatment is right for you.

How does tolvaptan work and what are its benefits?

Tolvaptan is a new medication that affects how the kidneys control the concentration of urine. Taking tolvaptan will cause you to produce a larger amount of more diluted urine. Your kidney doctor can tell you more about how the medication works.

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 would continue to decline, but at a slower rate.

For more information about kidney function, please see the Chronic Kidney Disease leaflet.

Who can take tolvaptan?

Tolvaptan is available to NHS patients who have rapidly progressing ADPKD and mild chronic kidney disease (known as CKD stage G2 and G3). Mild chronic kidney disease means you have less than 90% kidney function but more than 30% kidney function. Rapidly progressing means you are losing more than about 5% of your kidney function each year.

People with more than 90% kidney function can't be offered tolvaptan at this time, but it may be an option in the future if their kidney function worsens.

Tolvaptan has not been approved for use by NICE for people who have less than 30% kidney function.

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.

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 will also need to travel to Oxford for appointments for the first 18 months of treatment. This is because you will need to be closely monitored whilst receiving your tolvaptan treatment. This monitoring is carried out in the Oxford Kidney Unit and is coordinated by a multidisciplinary team made up of pharmacists and a nephrologist, based in Oxford (Oxford Tolvaptan team). Their contact details are available at the end of this leaflet.

You will need to have monthly blood tests for the first 18 months of treatment and every 3 months after that, until you stop taking tolvaptan. These blood tests need to be taken in hospital, so they can be reviewed by the team in Oxford. They can confirm it is safe for you to continue the treatment and release the next prescription.

In order to help us to continue to understand ADPKD, we will ask you to consider joining the Rare Disease Registry (RaDaR). RaDaR is a national database, which collects information about people with ADPKD.

Website: <http://rarerenal.org/radar-registry/>

Please speak to the Research Nurses if you want to know further information.

Tel: **01865 225 360**

PatientView

PatientView is individualised online information which is available for you to:

- find out your latest blood results
- find information about your kidney condition and treatment and other information about kidney diseases
- read your letters from the Renal Unit
- read about renal diets.

To find out more, please visit www.patientview.org

If you then wish to enrol, please speak to a member of your kidney team.

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 in the afternoon.

You will start on a low dose and this will be increased on a monthly basis, unless you have side effects.

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 avoid becoming excessively thirsty or dehydrated.

What should I do if I become unwell?

- If you have more than two episodes of vomiting or diarrhoea you should stop taking your tolvaptan tablets until your symptoms have settled.
- Continue to drink plenty of liquids (preferably water). Vomiting, diarrhoea and high temperatures can make you more likely to become dehydrated.
- Restart your tolvaptan once you have had no vomiting or diarrhoea for 24 hours.

Tolvaptan can occasionally cause inflammation in the liver. This can occur within the first few months of starting treatment. The inflammation is usually mild and improves when the medication is stopped. However, there is a small risk that this inflammation could be more severe. We can often see signs of this on your blood tests before you have any symptoms, which is why monitoring with blood tests is so important.

Some other medications can interact with tolvaptan. If a new medication is prescribed for you, remind the doctor you are

taking tolvaptan. Please avoid grapefruit juice, because it can interact with this medication.

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

Occasionally you may need to take a 'holiday' from taking 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, you should avoid doing this 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.

Please contact the Oxford Tolvaptan team if you have any symptoms you are concerned about (see the next page for contact details).

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 4 weeks before starting treatment with tolvaptan, during treatment with tolvaptan, and for at least a further 4 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, nurse or pharmacist.

We will discuss with you the most suitable form of contraception to use. 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

Oxford Tolvaptan Team

Nephrologist

Tel: **01865 228 681**

(during normal office hours – answerphone available)

Pharmacists

Tel: 01865 226 105

Email: orh-tr.oxfordtolvaptan@nhs.net

(Monday to Friday, 9.00am to 6.00pm)

Further information

You may find useful information on the following websites:

Oxford Kidney Unit

Website: www.ouh.nhs.uk/OKU

Polycystic Kidney Disease Charity

Website: <http://pkdcharity.org.uk/>

The Renal Association

Website: <http://rarerenal.org/rare-disease-groups/adpkd-rdg/>

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALS@ouh.nhs.uk**

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