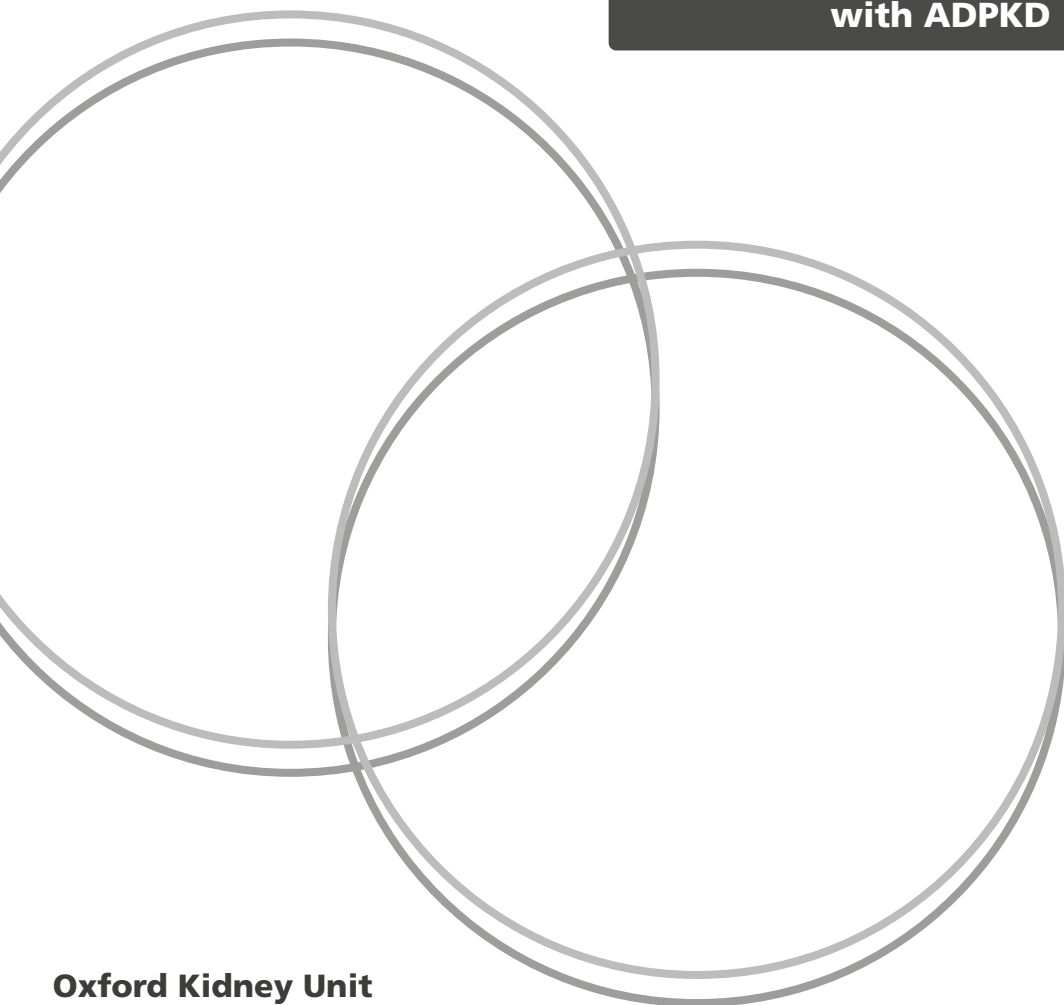




Oxford University Hospitals
NHS Foundation Trust

Tolvaptan for Adult Polycystic Kidney Disease (ADPKD)

Information for people
with ADPKD



Oxford Kidney Unit

What is tolvaptan?

Tolvaptan is the first 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. 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 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 adult 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. The tolvaptan clinics take place in Oxford or in Milton Keynes. You need to be closely monitored whilst you are taking tolvaptan. 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 or if your GP practice is able at your local GP surgery. Once the tolvaptan team have confirmed it is safe for you to continue the treatment they will 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.

Telephone: **01865 225 360**

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.

Some people may also experience other side effects including headaches and gout. If you'd like to discuss any concerns about side effects please contact the pharmacy team on the telephone number on page 9.

Tolvaptan can cause inflammation in the liver, in about 5% of people. 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.

What should I do if I become unwell?

Stop taking tolvaptan if you:

- have more than 2 episodes of vomiting or diarrhoea
- have a high temperature of above 38 degrees Celsius or are shivering or cannot stop shaking.

Restart tolvaptan when you have been free of the above symptoms for 24 hours.

Are there any interactions with tolvaptan?

Some other medications can interact with tolvaptan. If a new medication is prescribed for you, remind the doctor, dentist or other healthcare professional you are taking tolvaptan. You can also ring the pharmacy team on the telephone number on page 9 to check if a new medication is safe to take. Please avoid grapefruit juice, because it can interact with this medication.

What should I do if I miss a dose?

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.

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 years 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

Telephone: **01865 228 681**

(during normal office hours – answerphone available)

Pharmacists

Telephone: **01865 226 105**

Email: oxfordrenalpharmacists@ouh.nhs.uk

(Monday to Friday, 9.00am to 4.00pm)

Milton Keynes Reception

(appointments only)

Telephone: **01908 996 487**

Useful websites

Oxford Kidney Unit

Lots of information about the Oxford Kidney Unit for patients and carers.

Website: www.ouh.nhs.uk/oku

Kidney Care UK

A charity which has lots of practical support and information for people with kidney disease.

Website: www.kidneycareuk.org

Six Counties Kidney Patients Association

The SCKPA is run for patients by patients or family members.

They offer support to people suffering from kidney disease or who are on dialysis. They work closely with the Oxford Kidney Unit and have branches in Oxfordshire, Northamptonshire, Buckinghamshire, and Milton Keynes, and parts of Wiltshire, Gloucestershire and Berkshire.

Website: www.sixcountieskpa.org.uk

National Kidney Federation

A charity which has lots of practical support and information for people with kidney disease.

Website: www.kidney.org.uk

RareRenal (The Renal Association)

Run by UK based kidney doctors promoting research. There are links from the website to join the register and be the first to know about potential new treatments and clinical trials.

Register: www.rarerenal.org/radar-registry

Polycystic Kidney Disease Charity

Useful information for patients and their families

Website: www.pkdcharity.org.uk

OUH Patient Portal Health for Me

Please ask a member of the renal team to sign you up to the patient portal.

Website: www.ouh.nhs.uk/patient-guide/patient-portal

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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Oxford University Hospitals NHS Foundation Trust

www.ouh.nhs.uk/information



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