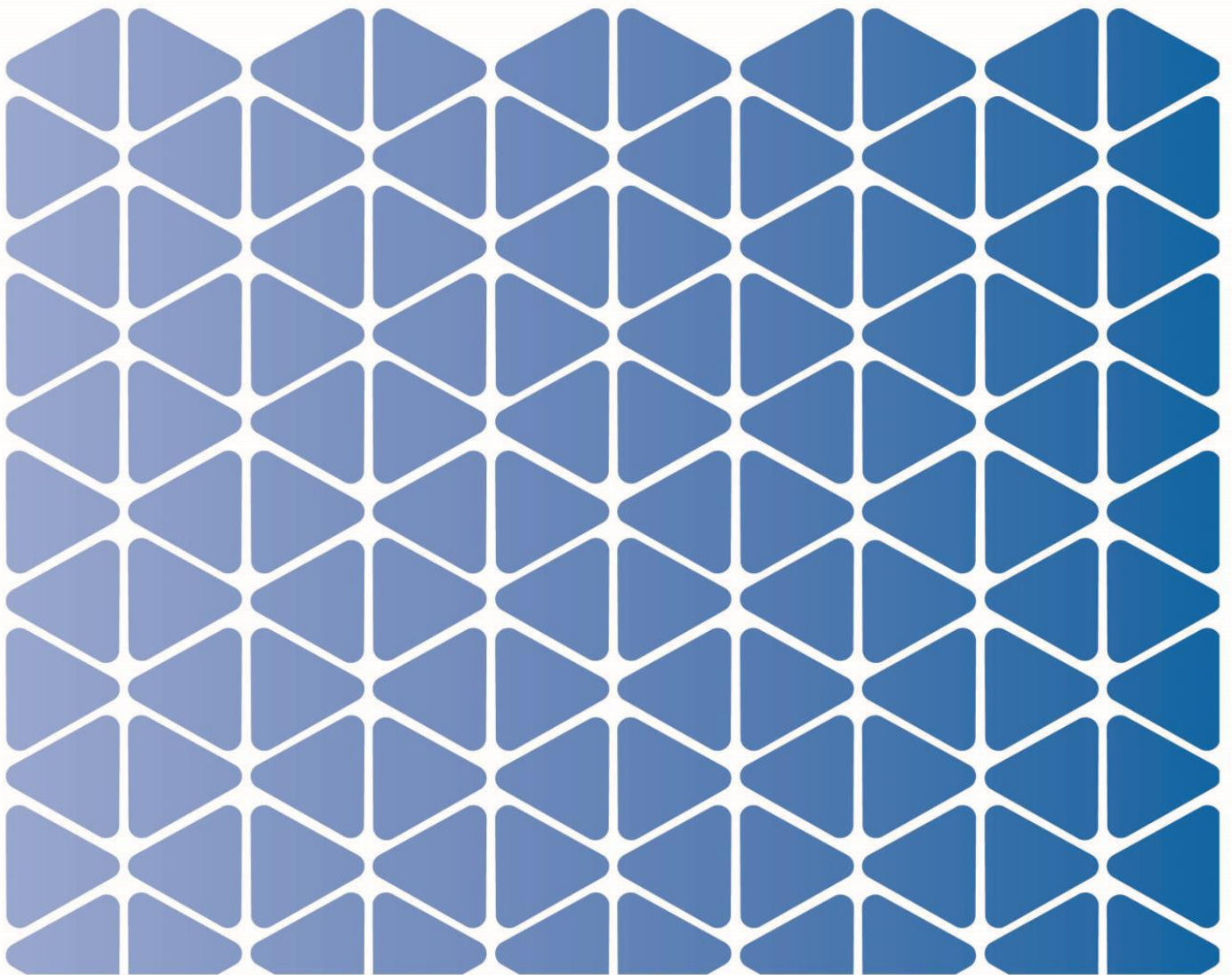


PATIENT INFORMATION

**TOLVAPTAN FOR THE TREATMENT OF
ADULT POLY CYSTIC KIDNEY DISEASE
(ADPKD)**



The aim of this leaflet is to provide information for patients with autosomal dominant polycystic kidney disease (ADPKD) who are considering Tolvaptan as a treatment option. This leaflet will not replace the information discussed between you and your doctor, but can act as a starting point for discussion or a reminder of key points.

What is Adult Poly Cystic Kidney Disease (ADPKD)

ADPKD is a genetic condition that causes small fluid filled sacs called cysts to develop in the kidneys. The growth of cysts causes the kidneys to become enlarged and interferes with their ability to filter waste products from the blood. This can lead to kidney failure.

ADPKD cannot be cured; however, it is possible to slow down the onset of kidney failure in some patients through the use of a medication called Tolvaptan.

What is Tolvaptan and what are the benefits?

Tolvaptan is a drug that was approved in 2015 by the National Institute of Health and Care Excellence (NICE) specifically for the treatment of ADPKD. In some patients, Tolvaptan has been shown to slow down the growth of kidney cysts, by blocking the hormone vasopressin that ordinarily encourages the cysts to grow. This may help to protect the function of your kidneys and delay the need for kidney transplant or dialysis.

Tolvaptan has also been shown to reduce kidney pain in some patients.

Who is suitable for Tolvaptan?

Tolvaptan can be offered to patients with a confirmed diagnosis of ADPKD who have chronic kidney disease stage 2-3 with evidence of rapidly progressive kidney disease. This will be outlined in more detail to you by your doctor. Tolvaptan is not suitable for patients who have the following: liver disease, you are allergic to Tolvaptan or any of the ingredients listed in this medication including lactose, you have difficulty recognising when you are thirsty or are unable to drink water, you are pregnant or breast feeding, you are unable or unwilling to comply with monthly blood tests

How long will Tolvaptan take to work?

You will notice the effects of taking Tolvaptan immediately. These include increased thirst and urine production. However, the effects of slowing cyst growth and decline in kidney function will only become apparent after long term treatment over a period of years. It is also important to understand that Tolvaptan will not stop the progression of your ADPKD. You may still develop cysts and eventually kidney failure. The overall aim of Tolvaptan treatment is to slow the speed at which this happens.

How should I take Tolvaptan tablets?

Tolvaptan tablets are taken twice daily.

They should be taken with water and swallowed whole (not broken into pieces or chewed).

The first dose should be taken in the morning. This is larger than the second dose which is taken later in the day.

The first (larger dose) should be:

- Taken upon waking and at least 30 minutes before food.

The second (smaller dose) should be:

- Taken 8 hours after the first dose and can be taken with food.

The total daily dose of Tolvaptan will be gradually increased over the first few months providing that you are tolerating it and it is not causing you any problems.

What are the side effects of taking Tolvaptan?

As with all medications there are potential side effects.

Due to its mode of action, you will feel more thirsty than usual and need to pass urine more frequently including during the night.

It is important that you drink a large volume of water (at least 5-6 litres is recommended but may vary from person to person) on a daily basis to avoid dehydration. You must not allow yourself to become excessively thirsty, this means that you will need to:

- Drink regularly during the day; it is advisable that you always have a drink with you.
- Drink one or two glasses of fluid before going to bed.
- When you get up to pass urine overnight have a drink of fluid.

Tolvaptan can cause liver abnormalities in some patients. These tend to return to normal when Tolvaptan is stopped. Hence strict monitoring of your liver function by a blood test will be performed whilst you are taking Tolvaptan.

Tolvaptan can also increase uric acid levels in the blood, which can cause gout. This can be treated with additional medication.

Does Tolvaptan interact with any food or medications?

Some medications and herbal remedies such as St Johns Wort can cause problems if they are taken whilst you are taking Tolvaptan. You must therefore inform any doctor or dentist who is prescribing new medication that you are taking Tolvaptan so that such problems can be avoided.

Grapefruit must also be avoided as it increases the effect of Tolvaptan.

Avoid drinking large quantities of alcohol as this can be very dehydrating.

Is there anything that I should look out for whilst taking Tolvaptan?

You should look out for signs of jaundice developing. This includes the following:

- Your skin becoming yellow
- The whites of your eyes becoming yellow
- Dark coloured urine
- Itching
- Feeling sick or being sick
- Abdominal (tummy) pain

If you experience any of these symptoms you must **Stop taking Tolvaptan and contact your renal team immediately.**

How will I be monitored?

Whilst receiving Tolvaptan treatment you will need to have monthly blood tests performed for the first 18 months to monitor your liver function closely. You may also need to attend clinic appointments more frequently than you are at present to allow for closer monitoring to take place.

You will be given a new supply of tablets when you attend your clinic visit.

It is important to remember that you can only get your supply of tablets from the renal clinic at the hospital. You will not be able to get your Tolvaptan tablets from your GP or local chemist.

What should I do if I forget to take Tolvaptan?

Take your next dose as normal. You must not take a double dose to make up for the dose that you missed. There may be occasions where you may need to take a “holiday” from Tolvaptan. For example if you are going on a long car journey, where access to toilet facilities may be limited. You may not wish to take Tolvaptan on that day. You should avoid doing this more than once a month otherwise you will not be receiving the full benefit of taking Tolvaptan.

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 resolved.

You must continue to drink plenty of fluids (preferably water) to avoid dehydration occurring.

Restart your Tolvaptan tablets once you have had no vomiting or diarrhoea for 24 hours.

Pregnancy and breastfeeding

If you are trying to become pregnant, or you are pregnant you should not take Tolvaptan as it may be harmful to your unborn baby.

Tolvaptan should also not be used whilst breast feeding.

If you are a woman of child bearing age you must use a reliable and effective method of contraception for at least four weeks before starting Tolvaptan, during treatment with Tolvaptan, and for at least a further four weeks after stopping Tolvaptan treatment.

If you are or think that you may be pregnant whilst taking Tolvaptan you must stop taking it immediately and inform your doctor.

Contact Information

For all enquiries please contact the renal team on 01905 7330239.

Further information

You may find useful information on the following websites:

The Renal Association

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

Polycystic Kidney Disease Charity

www.pkdcharity.org.uk

National Institute of health and Care Excellence (NICE)

<http://www.nice.org.uk/guidance/TA358>

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Worcestershire Royal Hospital

Questions I need to ask my doctor or nurse.

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.