

## Patient information

# Tadalafil Loin Pain Haematuria Syndrome (LPHS)

Nephrology-LUHFT

Generic name: Tadalafil

#### What is Tadalafil?

Tadalafil is a medication used to treat erectile dysfunction, benign prostate hyperplasia and pulmonary arterial hypertension (PAH).

## What is Loin Pain Haematuria Syndrome?

Loin pain haematuria syndrome (LPHS) is a very rare condition that causes severe pain in the loins or flanks (the part of the lower back below the ribs and above the pelvis) and blood in the urine. LPHS affects around 1 in 1,000,000 people in the UK. It was first identified in 1967 but there has been very little research on the condition so it is not well understood as to its cause.

## Why use Tadalafil?

Tadalafil has been used with some success in patients with LPHS. However, its use in LPHS is currently unlicensed. The use of unlicensed medication is permitted providing it justified and in the best interests of the patient especially for rare medical conditions. Consent will be taken after careful explanation of the risks and benefits by a Clinician who is experienced in the use of this drug. You will be monitored closely for effectiveness and any adverse side effects.

Tadalafil belongs to a class of drugs called phosphodiesterase type 5 (PDE5) inhibitors. Tadalafil works by relaxing the blood vessels and this is thought to be of help with the pain associated with LPHS.

## How is Tadalafil Taken?

- Tadalafil is taken orally, usually once daily.
- It can be taken with or without food.
- Follow your healthcare provider's instructions carefully. Do not change the dose or stop taking the medication without consulting your Consultant Nephrologist.

Dosage:

- The typical dose for used by our centre is to start at 5mg and increased every two
  weeks to a maximum daily dose of 20mg once daily.
- Your doctor may vary the dose depending on your pain.
- If you have no response to Tadalafil the drug will be discontinued by your Consultant Nephrologist.

#### Possible Side Effects:

## **Common side effects may include:**

- Headache
- Muscle aches
- Flushing (redness or warmth in the face, neck, or chest)
- Indigestion or upset stomach
- Nasal congestion
- Back pain

#### Rare but serious side effects:

- Sudden vision loss (could be a sign of non-arteritic anterior ischemic optic neuropathy, NAION)
- Sudden hearing loss or ringing in the ears
- Chest pain, irregular heartbeat, or shortness of breath (seek immediate medical attention)
- Prolonged or painful erection (priapism)

#### **Precautions:**

Inform your doctor if you have a history of heart disease, liver or kidney problems, or if you are taking nitrates (e.g., nitro-glycerine) or alpha-blockers. Tadalafil can interact with these medications and cause a dangerous drop in blood pressure.

Avoid alcohol, as it may increase the risk of side effects like dizziness or low blood pressure.

Tadalafil has not been licensed for patients under 18 years but has been used safely for children and young adults with pulmonary arterial hypertension.

## **Drug Interactions:**

- Nitrates (e.g., nitro-glycerine, isosorbide)
- Alpha-blockers (e.g., doxazosin, tamsulosin)
- Antihypertensive medications
- Certain antifungal or antibiotic medications (e.g., ketoconazole, rifampin)
- Grapefruit juice may increase the risk of side effects.

#### What to Do if You Miss a Dose:

Take the missed dose as soon as you remember. If it is almost time for your next dose, skip the missed dose and continue with your regular schedule. Do not double the dose.

## Storage:

- Store at room temperature, away from moisture and heat.
- Keep out of reach of children.

#### When to Contact Your Doctor:

If you experience severe side effects, such as vision or hearing changes, chest pain, or an erection lasting more than four hours.

#### **Additional Notes:**

Tadalafil is not a cure for LPHS, but it can help manage symptoms and improve pain control.

Regular follow-ups with your healthcare provider are essential to monitor your condition and adjust treatment as needed.

This information is not exhaustive. Always consult your healthcare provider or pharmacist for personalized advice and guidance.

#### **Feedback**

Your feedback is important to us and helps us influence care in the future. Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

## **Further information**

https://www.kidney.org.uk/loin-pain-haematuria-syndrome https://kidneycareuk.org/kidney-disease-information/kidney-conditions/loin-pain-haematuria-syndrome/

Phone number: 0151 529 3300

Author: Nephrology Review date: April 2028

All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل انتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرقة تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والكترونيا.

所有經信托基金批准的患者資訊均可以其它格式提供,包括其它語言、 易讀閱讀軟件、大字

體、音頻、盲文、穆恩體(Moon)盲文和電子格式,敬請索取。

در صورت تمایل میتوانید کلیه اطلاعات تصویب شده توسط اتحادیه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

ز انیاریی پیّو هندیدار به و نهخو شانه ی له لایه ن تراسته و ه پهسهند کراون، ئهگهر داوا بکریّت له فوّر ماته کانی تردا بریتی له زمانه کانی تر ، ئیزی رید (هاسان خویندنه وه)، چاپی گهوره، شریتی دهنگ، هیّلی موون و ئهلیّکتروّنیکی ههیه.

所有经信托基金批准的患者信息均可以其它格式提供,包括其它语言、易读阅读软件、大字体、音频、盲文、穆恩体(Moon)盲文和电子格式,敬请索取。

Dhammaan warbixinta bukaanleyda ee Ururka ee la oggol yahay waxaa marka la codsado lagu heli karaa nuskhado kale, sida luqado kale, akhris fudud, far waaweyn, dhegeysi, farta braille ee dadka indhaha la', Moon iyo nidaam eletaroonig ah.