Pitolisant for the treatment of narcolepsy

The purpose of this leaflet is to provide you with some information about pitolisant, which has been prescribed to treat your narcolepsy. If you have any questions or concerns, please speak to the doctor, pharmacist or nurse caring for you.

What is narcolepsy?
Narcolepsy is a long-term condition which causes excessive sleepiness during the day and may disrupt your sleep at night. You can also have sleep attacks where you fall asleep at inappropriate times during the day without any warning.

What is pitolisant?
Pitolisant belongs to a new group of medicines which regulate certain chemicals in the brain to promote wakefulness. It works by stimulating the brain to improve wakefulness and daytime alertness, while also helping to improve cataplexy attacks.

How do I take the medicine?
Pitolisant should be taken once a day, in the morning, for the treatment of narcolepsy. It can be taken with or after food. It should be swallowed whole with a glass of water. It is important to take pitolisant as your consultant has prescribed. Do not stop taking suddenly unless told otherwise.

What should I do if I forget to take the medicine?
Don’t worry. Just take the dose as soon as you remember, but do not take after 2pm as this may affect your sleep and reduce your total sleep time. Do not take two doses together to make up for the forgotten dose.

Are there any side effects?
In addition to their desired effects, most medicines can cause unwanted side effects, although not everyone gets them. The following are examples of some of the common side effects reported by patients taking pitolisant. The unwanted effects often fade as your body adjusts to the new medicine, but speak with your doctor or pharmacist if any of the following continue or become troublesome.

For further information on side effects, please see the manufacturer’s leaflet that comes with the medicine.

If any of the side effects persist or become a problem, contact your GP, consultant or pharmacist.
<table>
<thead>
<tr>
<th>Side effect</th>
<th>What should I do if it happens?</th>
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</thead>
<tbody>
<tr>
<td></td>
<td><strong>Common (between one in 100 and one in 10)</strong></td>
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<tr>
<td>Sleep disorders – insomnia, fatigue</td>
<td>Speak with your consultant if this continues and is troublesome as your dose may need to be reduced.</td>
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<tr>
<td>Headache</td>
<td>Drink plenty of water and take your usual painkiller, for example, paracetamol. If headache persists, discuss with your consultant as your dose may need to be reduced.</td>
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<tr>
<td>Feeling or being sick</td>
<td>Stick to simple meals – avoid rich or spicy foods. If symptoms of indigestion and acid reflux persist, a tablet can be given to stop acid being produced in your stomach.</td>
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<tr>
<td>Indigestion</td>
<td></td>
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<tr>
<td>Dizziness, vertigo</td>
<td>If this happens, do not drive and do not use tools or machinery.</td>
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<tr>
<td>Tremors</td>
<td>Speak to your doctor if this continues or becomes troublesome.</td>
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**Important**: if you experience any of the following symptoms, stop taking pitolisant and contact your doctor for advice straight away.
- A rash or blisters on the skin.
- Fast heartbeat or palpitations.
- Any changes to your mood, behaviour, or thinking.
- Any suicidal thoughts, or thoughts about harming yourself.
- Significant weight changes.

**Can I take pitolisant with other medicines?**
Pitolisant may interact with some medicines. It is important to let us know about any medicines that you are currently taking, so that we can check pitolisant is suitable for you. If you are buying any medicines over the counter from a pharmacy, always mention that you have been prescribed pitolisant. It is safe to take paracetamol with this medicine but ask for advice before buying any anti-inflammatory painkillers, such as ibuprofen or aspirin. Seek advice when purchasing herbal or homeopathic remedies.

**Is there anything else I need to know?**
Pitolisant can reduce the effectiveness of all hormonal contraceptives – other forms of effective contraception should be used while taking pitolisant.

**Pregnancy and breastfeeding**: Pitolisant is not recommended for use during pregnancy and would need to be excluded prior to commencing treatment. Women of childbearing age should use effective contraception during treatment and for up to at least 21 days after treatment is stopped. If you are considering becoming pregnant, or you discover that you are pregnant, you should discuss this with your consultant as soon as possible so that a management plan can be agreed. Pitolisant should not be used if breastfeeding.
Narcolepsy and driving: In the UK, you are required by law to let the Driver and Vehicle Licensing Authority (DVLA) know if you are diagnosed with narcolepsy. You may be allowed to drive again when your symptoms are well controlled with medication, but you will need to have regular reviews.

Pitolisant has little effect on the ability to drive and use machinery. However you must be aware that your level of wakefulness may not return to normal despite taking pitolisant. Your sleepiness should be frequently reassessed and you may be advised to avoid driving or other potentially dangerous activities. Your consultant will advise you about this. Even if your driving ability is not impaired, if you drive, you are advised to carry some evidence with you which shows that the medicine has been prescribed for you – a repeat prescription form or the patient information leaflet from the packet is generally considered suitable.

If you are due to have an operation or dental treatment, it is important that you tell your dentist, consultant or GP who can advise you further.

Sleep hygiene: Taking pitolisant is not a replacement for a good sleep routine. It is still important to aim to get around seven to eight hours of sleep at night if possible. It is advisable to go to bed when tired and get up at about the same time each day.

Pitolisant should be stored safely and kept out of reach of children. If anyone other than you takes this medicine, you, they, or their parent/carer should contact NHS 111 for advice. If they are unwell then they should call for an ambulance.

The expiry date is printed on the container. Do not use the medicine after this date. The remainder should be returned to your local pharmacy to be thrown away.

How will my treatment be reviewed?
Your treatment will be reviewed on an ongoing basis at the Sleep Centre and the dose adjusted depending on your symptoms. This will be a long-term treatment if it is of benefit. Your consultant will want to check to ensure that the treatment is helping. You may need to have your blood pressure and heart rate checked regularly.

How do I get a repeat prescription?
The Sleep Centre at Guy’s Hospital will provide you with a repeat prescription for your pitolisant. Please note that this prescription can only be used at the hospital Outpatient Pharmacy and will not be accepted in your local community pharmacy.

Useful sources of information
Narcolepsy UK, w: www.narcolepsy.org.uk. You might find this charity’s website useful for connecting with patients who suffer from the same condition as you, but any information found should not alter your current treatment. You should discuss any new advice with the doctor caring for your condition.
Contact us
If you have any questions or concerns about your sleep disorder please contact the Sleep Disorder Centre, t: 020 7188 3430, Monday to Friday, 9am to 5pm.

Out of hours, please leave a message and a member of staff will call you back during working hours, or contact your GP or NHS 111.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline
If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.
t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.
t: 020 7188 8801 (PALS) e: pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) e: complaints2@gstt.nhs.uk

Language and Accessible Support Services
If you need an interpreter or information about your care in a different language or format, please get in touch.
t: 020 7188 8815 e: languagesupport@gstt.nhs.uk

NHS 111 – out of hour’s advice
Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.
t: 111

NHS website
Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.
w: www.nhs.uk

Get involved and have your say: become a member of the Trust
Members of Guy’s and St Thomas’ NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:
t: 0800 731 0319 e: members@gstt.nhs.uk w: www.guysandstthomas.nhs.uk/membership