

Methylphenidate for the treatment of narcolepsy

The purpose of this leaflet is to provide you with some information about methylphenidate, 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 methylphenidate?

Methylphenidate belongs to a group of medicines called stimulants. It can be used to treat some of the symptoms of narcolepsy. Methylphenidate works by stimulating your brain to increase alertness and reduce excessive sleepiness during the day. Although there is no cure for narcolepsy, methylphenidate can help to control your symptoms.

Methylphenidate is available in both a modified-release and an immediate-release preparation. The modified-release preparation simply means that the medicine is released slowly during the day, to give a longer effect. These brands have the letters 'XL' after the brand name, and they usually only need to be taken once a day. With immediate-release preparations, the medicine is released quicker and the effects don't last as long. These usually need to be taken more than once a day.

Taking an unlicensed medicine

The use of methylphenidate for narcolepsy is unlicensed, which means that although the manufacturer of the medicine has not specified it can be used in this way, there is evidence that it works to treat this particular condition. The leaflet, **Unlicensed medicines – a guide for patients**, has more information about unlicensed medicines. If you would like a copy, please ask your doctor, nurse or pharmacist. Alternatively you can call the Pharmacy Medicines Helpline – contact details are at the end of this leaflet.

How do I take the medicine?

When starting methylphenidate, your consultant will give you a small dose initially and then increase accordingly in response to your symptoms. Methylphenidate XL should be taken and swallowed **whole** with water. It is usually taken once a day in the morning. It **must not** be chewed, divided or crushed. You can take the medicine with or without food, but taking it after food may help to minimise any stomach upsets. It is important to take your dose at the same time each day as this will help prevent you from missing any doses.

Methylphenidate immediate-release tablets should be taken and swallowed with water. To begin with you may be prescribed just one or two doses every day, but this may be increased up to three doses every day. You may have been prescribed these methylphenidate tablets in addition to your XL tablets as a boost during the day.

Make sure you take methylphenidate exactly how your consultant or pharmacist tells you. It is usual to take the XL preparation ONCE a day in the morning, but sometimes you may need to split your dose and take one tablet in the morning and another one at lunchtime. Your second dose should be no later than 2pm as this may affect your sleep and reduce your total sleep time. If you are taking methylphenidate immediate-release tablets, you should take them no later than 3pm as this may affect your sleep and reduce your total sleep time.

What should I do if I forget to take the medicine?

Don't worry. Just remember to take the next dose when it is due. **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 experiences them. The following are examples of some of the common side effects reported by patients taking methylphenidate (up to one in one hundred patients). The unwanted effects often fade as your body adjusts to the new medicine, but speak with your GP 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.

Side effect	What should I do if it happens?
Feeling or being sick Tummy (abdominal) pain Indigestion	Stick to simple meals – avoid rich or spicy foods. Taking methylphenidate after meals may help.
Headache	Drink plenty of water and take your usual painkiller, for example, paracetamol. If the headache continues, speak with your GP.
Feeling sleepy, dizzy, or tired	If this happens, do not drive or use tools and machinery.
Diarrhoea	Drink plenty of water. This will help to replace lost fluids.
Cough and cold-like symptoms Loss of appetite, weight or hair Sleeping problems Dry mouth Itchy rash High temperature (fever) Muscle pain Unusual body movements or tics	If any of these become troublesome, speak with your doctor.

Important: if you experience any of the following symptoms, stop taking methylphenidate and contact your doctor for advice **as soon as possible**:

- Any changes to your mood, behaviour, or thinking.
- Chest pain, fast heartbeat, or unexplained breathlessness.
- Any suicidal thoughts, or thoughts about harming yourself

If any of the side effects persist or become a problem, contact your GP, consultant or pharmacist

Can I take methylphenidate with other medicines?

Methylphenidate may interact with some medicines. It is therefore important to let us know about any medicines that you are currently taking so that we can check methylphenidate is suitable for you. If you are buying any medicines over the counter from a pharmacy always mention that you have been prescribed methylphenidate. It is safe to take paracetamol and ibuprofen with this medicine. Advice should be sought when purchasing herbal or homeopathic remedies.

Is there anything else I need to know?

Do not drink alcohol while on methylphenidate. Alcohol will increase the risk of side effects such as mood changes, confusion, sleep disturbances, increased drowsiness so it is not recommended.

Taking methylphenidate can lead to your body becoming dependent on it, therefore you should not stop taking methylphenidate unless your consultant tells you to do so as stopping abruptly may cause side effects such as extreme fatigue. It is recommended that your dose should be reduced gradually if stopping treatment. This will be discussed with you before you start treatment.

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

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. Your consultant will advise you about this. If you are a driver, please be aware that methylphenidate may affect your reactions and ability to drive. It is an offence to drive while your reactions are impaired. Even if your driving ability is not impaired, if you drive, you are advised to carry with you some evidence that the medicine has been prescribed for you – a repeat prescription form or a patient information leaflet from the pack is generally considered suitable.

Pregnancy and Breast Feeding: Methylphenidate is not recommended for use during pregnancy. If you are considering becoming pregnant, or you discover that you are pregnant, you should discuss with your consultant so that a management plan can be agreed.

Sleep hygiene: Taking methylphenidate 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. Patients should be advised to go to bed when tired and get up at about the same time each day.

Methylphenidate is a controlled drug. It should be stored safely and kept out of reach of children. 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 in response to 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?

Your GP will give you a repeat prescription for methylphenidate. Please ensure you request your repeat prescription early so that you don't run out or risk missing any doses of your medication.

If your GP won't supply your methylphenidate, the Sleep Centre will continue to provide you with a prescription which you can take to the Outpatient Pharmacy on site for supply. Please be aware 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 – Supporting people with narcolepsy. You might find this charity's website – www.narcolepsy.org.uk – useful for connecting with patients who suffer from the same condition as you but any new information found should not alter your current treatment regimen and 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 on 020 7188 3430 (9am to 5pm).

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

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 Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health. **w:** www.nhs.uk

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