

Methylphenidate

Information for patients



**Cardio-Respiratory
Service**

This leaflet contains information about methylphenidate to treat narcolepsy and idiopathic hypersomnolence. It will give you more information about this medication.

You will normally be under the care of:

Dr Ghosh, Dr Ting, Dr Palissery

If you need to get in touch with one of the doctors or the specialist nurses, their contact numbers are:

Contact details:

Sleep Service: 0113 206 6040

(Sleep Service answer phone - choose option 1)

Appointment queries: 0113 206 6075

Email: leeds.sleep@nhs.net

Dr Ghosh/Ting/Palissery's Secretary: 0113 206 5863

This leaflet contains information about methylphenidate to treat narcolepsy and idiopathic hypersomnolence

It tells you:

- how the medicine works
- how you should take it
- whether there are any side-effects

Please also read the leaflet called **Unlicensed Medicines: Information for Patients** and any information provided by the manufacturer in the medicine package.

Why have I been given this leaflet?

The leaflet will help you to remember what your doctor has told you about this medicine. It will also help you to decide whether you want to go ahead with the treatment.

For most medicines, information is provided by the manufacturer in the medicine package. In the UK, this medicine does not have a licence for use in narcolepsy so the leaflet in the medicine package doesn't tell you everything you need to know. We have written this leaflet to give you some extra information.

So this medicine does not have a licence. What does this mean?

The leaflet called **Unlicensed Medicines: Information for Patients** tells you more about medicine licensing regulations. It also tells you why unlicensed medicines are sometimes used.

Why does methylphenidate not have a licence?

Sometimes a medicine has been licensed for a certain use and later use shows that it works for a different illness. The manufacturer can choose whether they apply to the Government to have the more recent information added to the licence. This costs a lot of money so sometimes the manufacturer decides it is not worth their while

Methylphenidate is a medicine that is licensed for use for Attention-Deficit Hyperactivity Disorder (ADHD) in children and adults.

Remember that your doctor will have thought carefully about which medicine is best for your condition.

What is narcolepsy?

Narcolepsy is a long-term condition that causes a person to suddenly fall asleep at inappropriate times. The brain is unable to regulate sleeping and waking patterns normally, which can result in excessive daytime sleepiness and possible sleep attacks where you may fall asleep suddenly and without warning.

What is idiopathic hypersomnolence?

Idiopathic hypersomnolence is a condition that causes excessive daytime sleepiness due to an unknown cause.

What is methylphenidate and how does it work?

Methylphenidate belongs to a group of medicines known as stimulants and it can be used to treat some of the symptoms of narcolepsy and idiopathic hypersomnolence.

Methylphenidate works by stimulating your brain making it more alert and reducing excessive daytime sleepiness. There is no known cure for narcolepsy or idiopathic hypersomnolence, but methylphenidate can be used to help manage your symptoms.

Methylphenidate is available in both a modified-release and an immediate-release preparation. The modified-release preparation means 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. Your consultant will decide which is the best preparation for you to take.

How should I take methylphenidate?

Your consultant will decide the best dose for you, but usually you will start on a low dose and then the dose will increase according to your response.

Methylphenidate modified-release (XL) tablets should be taken and swallowed whole with water, and it is usually taken ONCE a day in the morning. In some people, rebound hyperactivity disorder may occur if the effect of the drug wears off in the evening, and so your doctor may prescribe you an additional dose later in the day, which may eliminate this difficulty, but may disturb sleep.

Methylphenidate modified-release (XL) tablets must not be chewed, divided or crushed. You can take the medicine with or without food, but taking it after food may help to reduce stomach upset. It is important to take your dose at the same time each day as this will help prevent you from missing any doses.

You may also be prescribed some methylphenidate immediate-release tablets in addition to your XL tablets as a boost during the day. Methylphenidate immediate-release tablets should be taken 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. Make sure you take methylphenidate exactly how your consultant or pharmacist tells you.

If you forget to take your medication, 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 doses.

Do not take or use this medicine if you:

- are pregnant or planning on getting pregnant
- are breast feeding
- are allergic to methylphenidate
- have glaucoma
- have a diagnosis of phaeochromocytoma
- have hyperthyroidism/thyrotoxicosis
- have a diagnosis or history of severe depression, anorexia nervosa/anorexic disorders, suicidal tendencies, psychotic symptoms, severe mood disorders, mania, schizophrenia, psychopathic/borderline personality disorder
- have a diagnosis or history of severe and episodic (Type I) Bipolar (affective) Disorder (that is not well-controlled)
- have pre-existing cardiovascular disorders including severe hypertension, heart failure, arterial occlusive disease, angina, haemodynamically significant congenital heart disease, cardiomyopathies, myocardial infarction, potentially life-threatening arrhythmias and channelopathies (disorders caused by the dysfunction of ion channels)

- have pre-existing cerebrovascular disorders cerebral aneurysm, vascular abnormalities including vasculitis or stroke

Are there any side-effects?

Most medicines cause side-effects. The manufacturer's leaflet contains a list of the known side-effects for this medicine. Everyone reacts differently to medicines. You may have some side-effects or none at all. If you have any of these side-effects, you do not need to contact the doctors unless they persist for more than a few days or become unbearable. However, there are some rare but serious side-effects that you would need to tell your doctor about immediately.

Methylphenidate can commonly cause headaches so it is important to stay hydrated and drink plenty of water. If headaches persist or are severe please speak to your doctor. Methylphenidate can also commonly cause you to feel sleepy or dizzy or you may have nervousness and insomnia, if this happens do not drive or use tools and machinery.

In some patients, methylphenidate can cause a feeling of sickness or vomiting, diarrhoea, loss of appetite, indigestion, abdominal pains or dry mouth. To try and reduce these stomach effects, take your methylphenidate after food and avoid rich or spicy foods.

Other possible side-effects can include hair loss and skin rashes. If these side-effects become troublesome then speak to your doctor.

Speak to your doctor if you develop any new symptoms after starting methylphenidate.

Things to tell your doctor immediately

If you have any of the following, tell your doctor immediately:

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

Will I need any tests when taking methylphenidate?

There are some tests you may need to undergo before initiating methylphenidate, and these include:

- Blood pressure
- Heart rate
- Weight and height

These tests are usually carried out before commencing methylphenidate, following any dose adjustments and usually every 6 months whilst you are taking methylphenidate.

Will methylphenidate affect any other medicines?

Tell your doctor or pharmacist about all the other medicines you take. This includes any medicines you have had prescribed by another doctor as well as medicines bought from a pharmacy or supermarket and any herbal remedies.

Whenever you are prescribed a new medicine, or want to buy a medicine e.g. from a pharmacy or supermarket, it is important that you tell the doctor or pharmacist about all the medicines that you take, including methylphenidate. You should also tell your dentist when you see him/her.

Can I drink alcohol while I am taking methylphenidate?

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.

Where should I store methylphenidate at home?

You should always store methylphenidate in a safe place, which is cool, dry and away from direct sunlight. Methylphenidate is a controlled drug. 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 disposed of.

It is important that all medicines are stored out of reach of children.

Where do I get my next supply?

When you are on a steady dose of methylphenidate, your GP should take over prescribing it. Until then, this will be supplied when you come to the Clinic. You must make sure you get any repeat prescriptions to the pharmacy in good time. The pharmacy may not have the medicine in stock and may need a few days to arrange a supply.

Is there anything else I need to know?

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.

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.

How can I find out more?

Your agreement should be obtained before prescribing any medicine.

This leaflet has been written to provide general information about methylphenidate. If you have any further questions or concerns, please speak your doctor or pharmacist.



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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