

Sodium oxybate (Xyrem®) for the treatment of cataplexy in narcolepsy

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

What is cataplexy in 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. Cataplexy is a condition associated with narcolepsy that results in sudden muscle weakness triggered by strong emotions such as laughter, anger, fright or surprise. Muscle weakness can vary in severity, and cataplexy attacks can differ in both nature and length.

What is sodium oxybate?

Sodium oxybate is used to treat cataplexy but can also help with many of the other symptoms of narcolepsy. Sodium oxybate promotes deep sleep and improves night-time sleep. It helps with excessive daytime sleepiness as well as helping to control cataplexy. It is sometimes used in combination with other medicines for narcolepsy.

How do I take the medicine?

Sodium oxybate is taken in two doses – the first is taken as you go to bed and the second dose is taken 3 – 4 hours later. You should prepare both doses before you go to bed, and you may need to set an alarm to make sure you wake up to take the second dose. Although it seems to be at odds with getting a good night's sleep, it is important to follow these instructions. The medicine comes as a liquid and the doses should be drawn up using a syringe, and mixed with water in the special child-resistant dosing cups that come with the medicine. The manufacturer's leaflet supplied with the medicine explains how this should be done – please refer to this for further information.

Sit upright while taking your doses. Take your second dose while still in bed and lie down again straight away.

As food interferes with how much of this medicine is absorbed by your body, you should take sodium oxybate well after eating any food, for example, at least two to three hours after your evening meal.

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

If you forget to take the first dose, take it as soon as you remember and then take the second dose 3 – 4 hours later. If you miss the second dose, do not take it when you remember (or wake up), but instead skip the dose completely and do not take any more until the following evening. **NEVER take two doses together to make up for a 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 sodium oxybate (up to one in one hundred patients). 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

Side effect	What should I do if it happens?
Feeling dizzy	Move around more slowly. Do not drive and do not use tools or machinery until you feel better
Feeling sick	Stick to simple meals – avoid rich or spicy food
Headache	Drink plenty of water and take your usual painkiller, for example, paracetamol
Bedwetting	Avoid excess fluids before bedtime. Inform your doctor if this continues.

Important: if you experience any of the following symptoms, contact your consultant or GP for advice **as soon as possible**:

- Sleepwalking
- Any changes to your mood, behaviour, or thinking.
- Any suicidal thoughts or thoughts about harming yourself.
- Significant change in weight and/or appetite

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

Can I take sodium oxybate with other medicines?

Sodium oxybate 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 sodium oxybate is suitable for you. If you are buying any medicines over the counter from a pharmacy, always mention that you have been prescribed sodium oxybate. It is safe to take paracetamol and ibuprofen with this medicine but always ask your pharmacist first. Advice should be sought when purchasing herbal or homeopathic remedies.

Is there anything else I need to know?

Treatment with sodium oxybate is usually long-term. Continue to take the medicine unless you are advised otherwise. Stopping suddenly can cause problems and your doctor may want you to reduce your dose gradually if this is necessary.

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 sodium oxybate 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, do not drive within six hours of taking a dose of sodium oxybate. You may also continue to feel sleepy during the following day, so do not drive and do not use tools or machinery if this happens, as you may put yourself and others at risk. 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: Sodium oxybate 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 sodium oxybate 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.

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.

Do not drink alcohol while you are on sodium oxybate, as it may increase the risk of side effects such as mood changes, confusion, reduced breathing rate, sleep disturbances. Sodium oxybate is known to cause dependence, particularly where more than the recommended doses are taken. If you are concerned about this, you should discuss it with your doctor.

Sodium oxybate contains a significant amount of sodium so you should limit your sodium intake, particularly if you are sensitive to salt intake, for example, if you have high blood pressure. Once a bottle has been opened it will keep for 40 days. After this time, make sure you have a fresh supply. Diluted liquid should only be kept for 24 hours.

Sodium oxybate 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. Any unused medicine, and diluted medicine which was not used, 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. 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?

Guy's Hospital Sleep Centre will provide you with a repeat prescription for your sodium oxybate, which will be dispensed by Lloyd's Outpatient pharmacy which is located on site.

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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