

# Your child's medication: Sodium oxybate for narcolepsy with cataplexy

## Information for children, families and carers

We have given you this factsheet because your child has been diagnosed with a condition called narcolepsy with cataplexy (sudden muscle weakness) and has been prescribed a medication called sodium oxybate as part of their treatment programme. This factsheet explains how your child should take sodium oxybate. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

Please note that our information may differ from that provided by the medication manufacturer. This is because their information usually relates to adults.

### **Sodium oxybate**

Sodium oxybate is a central nervous system depressant which reduces excessive daytime sleepiness and cataplexy in people with narcolepsy.

### **How does sodium oxybate help to treat narcolepsy with cataplexy?**

Narcolepsy is a long-term condition which disrupts the normal sleep/wake cycle.

Common symptoms of narcolepsy include:

- falling asleep at inappropriate times during the day
- fragmented night-time sleep
- excessive daytime sleepiness

In addition to this, some people experience sudden muscle weakness or loss of muscle control, known as cataplexy. This can be triggered by strong emotions such as laughter, anger, surprise or fright.

There is no known cure for narcolepsy. However, we can help to manage your child's symptoms with a combination of:

- scheduled daytime naps
- lifestyle changes
- sodium oxybate medication and/or other medications

Sodium oxybate promotes deep sleep. It stimulates 'GABA' receptors in the brain which switch the brain into a deep sleep state. Taking sodium oxybate at bedtime can help to reduce the symptoms of cataplexy and of feeling excessively tired during the day. It can also help if your child's sleep is poor, or if they have sleep-related hallucinations.

## **Is sodium oxybate suitable for everyone?**

Your child should not have sodium oxybate if they:

- have a drug or alcohol problem
- have severe depression
- take strong painkillers (such as morphine)

## **How to take sodium oxybate**

Sodium oxybate comes as a liquid that must be diluted with water. Please read the manufacturer's instructions that come with the medication.

The medication must be taken at bedtime and should start to work 5 to 20 minutes after your child takes it. It may take several weeks to notice any effect on your child's daytime symptoms.

**Your child should not stop taking sodium oxybate suddenly or without the support of our sleep clinic.**

## **Dose**

Sodium oxybate comes as a liquid preparation with 0.5mg in 1ml. We will prescribe your child a low dose to start with. We will increase the dose gradually to avoid side effects and to control your child's symptoms. We will discuss your child's dose regime with you.

It is important that you follow the instructions about how much your child should take. The dose will be shown on the medication label.

## **Storage**

Keep your child's medication in a locked cupboard.

## **Other medications**

Check with us before your child takes any new medication while they are taking sodium oxybate. Your child must not take benzodiazepines (such as clonazepam or diazepam).

Check with your pharmacist before your child takes any over-the-counter medication.

## Alcohol

Your child must not have any alcohol while they are taking sodium oxybate.

## Pregnancy and breastfeeding

Sodium oxybate should only be taken during pregnancy if the benefits outweigh the risks.

Contact us for advice if your child:

- is pregnant
- thinks they may be pregnant
- is planning to have a baby
- is breastfeeding

## Travel

If you need a letter in order to travel abroad with your child's medication, please contact us as soon as possible so we can arrange this.

## Monitoring

Before your child starts taking sodium oxybate, we will check their height and weight. We will then need to see your child in our sleep clinic regularly while they are taking sodium oxybate.

## What if my child takes too much sodium oxybate?

It can be dangerous to take too much sodium oxybate.

If your child takes too much sodium oxybate, call NHS **111** for advice and have the medication or packaging to hand. In an emergency, take your child to your nearest emergency department. Make sure to take your child's medication container and packaging in with you, even if it is empty. This will help the healthcare professional caring for your child.

## What if my child misses a dose of sodium oxybate?

Do not give your child the missed dose. Give the next dose at the usual time. **Never give a double dose of sodium oxybate.**

## What if my child is sick (vomits) after taking a dose of sodium oxybate?

Do not repeat the first dose. This is because it can be difficult to know how much was absorbed.

## Side effects

As with all medications, there may be side effects with taking sodium oxybate. We will prescribe your child a low dose to start with, to reduce the chance of side effects.

### Common side effects

- Night-time incontinence (bedwetting) - You may wish to use protective sheets on your child's bed until you are confident this will not be a problem. If it does happen, be reassured that for most children, this is temporary.
- Nausea and/or diarrhoea - When your child first starts taking sodium oxybate, they may feel slightly sick in the morning and lose their appetite. To help with this, your child should try to have a small plain breakfast.
- Sleep walking
- Sleep disordered breathing - This may be noticed by other family members as heavy snoring at night. If this happens, tell us.

For a full list of possible side effects, please see the manufacturer's leaflet that comes with your child's medication.

If your child experiences any of the side effects listed above, or you have concerns about your child, please contact us for advice. Outside of our working hours, contact NHS 111 for advice.

### General advice for medication

- Try to give your child their medication at the same time(s) each day to help you remember.
- Never give your child's medication to anyone else, even if their condition appears to be the same, as this could be dangerous.
- **If you think that someone else has taken your child's medication by accident, contact the person's general practitioner (GP) or NHS 111 immediately, or take them to the nearest emergency department if they are unwell.**
- If you think the medication is not working, contact us but continue to give the medication as usual. Do not give any extra doses as this may be dangerous.
- Make sure that your child always has enough medication. Order a new prescription at least two weeks before it runs out.
- Make sure that the medication your child has at home has not reached the 'best before' or 'use by' date on the packaging. Give old medication to your local pharmacy to dispose of.

## Contact us

If you have any questions or concerns, please contact us.

Sleep clinic

Telephone: **023 8120 5922** (Monday to Friday, 9am to 5pm)

Email: [paedssleepadmin@uhs.nhs.uk](mailto:paedssleepadmin@uhs.nhs.uk)

## Useful links

[www.nhs.uk/conditions/narcolepsy](http://www.nhs.uk/conditions/narcolepsy)

[www.medicinesforchildren.org.uk/advice-guides/general-information-about-medicines/unlicensed-medicines](http://www.medicinesforchildren.org.uk/advice-guides/general-information-about-medicines/unlicensed-medicines)

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