MSK Kids

PATIENT & CAREGIVER EDUCATION

Sodium Oxybate

This information from Lexicomp® explains what you need to know about this medication, including what it's used for, how to take it, its side effects, and when to call your healthcare provider.

Brand Names: US

Lumryz; Lumryz Starter Pack; Xyrem

Brand Names: Canada

Xyrem

Warning

- This drug can cause severe side effects. These may include breathing problems, low blood pressure, changes in alertness, and passing out. If you have questions, talk with the doctor.
- Abuse and misuse of this drug by itself or with certain other drugs may cause seizures, slow or shallow breathing, changes in alertness, coma, or death.

Sodium Oxybate 1/12

What is this drug used for?

- It is used to treat sudden loss of muscle tone (cataplexy) in patients with narcolepsy.
- It is used to treat a lot of sleepiness during the day in patients with narcolepsy.

What do I need to tell the doctor BEFORE my child takes this drug?

- If your child is allergic to this drug; any part of this drug; or any other drugs, foods, or substances. Tell the doctor about the allergy and what signs your child had.
- If your child has liver disease.
- If your child has succinic semialdehyde dehydrogenase deficiency.
- If your child drinks alcohol or takes any drugs that have alcohol.
- If your child is taking any drugs or natural products used for sleep. There are many products used for sleep. Ask your child's doctor or pharmacist if you are not sure.

This is not a list of all drugs or health problems that interact with this drug.

Tell the doctor and pharmacist about all of your child's drugs (prescription or OTC, natural products, vitamins)

Sodium Oxybate 2/12

and health problems. You must check to make sure that it is safe to give this drug with all of your child's other drugs and health problems. Do not start, stop, or change the dose of any drug your child takes without checking with the doctor.

What are some things I need to know or do while my child takes this drug?

- Tell all of your child's health care providers that your child is taking this drug. This includes your child's doctors, nurses, pharmacists, and dentists.
- Long-term or regular use of this drug may lead to dependence. Stopping this drug all of a sudden may lead to signs of withdrawal. Talk to your child's doctor before you lower the dose or stop giving this drug. You will need to follow the doctor's instructions. Tell your child's doctor if your child has any bad effects.
- Have your child avoid tasks or actions that call for alertness for at least 6 hours after taking this drug. These are things like riding a bike, playing sports, or using items such as scissors, lawnmowers, electric scooters, toy cars, or motorized vehicles. Have your child avoid these tasks or actions until your child feels fully awake.
- Alcohol may interact with this drug. Be sure your child does not drink alcohol.

Sodium Oxybate 3/12

- Talk with your child's doctor before your child uses marijuana, other forms of cannabis, or prescription or OTC drugs that may slow your child's actions.
- Many drugs interact with this drug and can raise the chance of side effects like deadly breathing problems.
 Talk with your child's doctor and pharmacist to make sure it is safe to give this drug with all of your child's drugs.
- After giving this drug, it is likely your child will fall asleep very fast (most of the time within 5 to 15 minutes). The time that it takes to fall asleep can change from night to night. Falling asleep all of a sudden when standing or rising from bed has led to falls and the need to go to the hospital. Be sure your child takes this drug while in bed. Have your child lie down right away after taking it.
- If your child is on a low-sodium or sodium-free diet, talk with the doctor. Some of these products have sodium.

If your child is pregnant or breast-feeding a baby:

 Talk with the doctor if your child is pregnant, becomes pregnant, or is breast-feeding a baby. You will need to talk about the benefits and risks to your child and the baby.

Sodium Oxybate 4/12

What are some side effects that I need to call my child's doctor about right away?

WARNING/CAUTION: Even though it may be rare, some people may have very bad and sometimes deadly side effects when taking a drug. Tell your child's doctor or get medical help right away if your child has any of the following signs or symptoms that may be related to a very bad side effect:

- Signs of an allergic reaction, like rash; hives; itching; red, swollen, blistered, or peeling skin with or without fever; wheezing; tightness in the chest or throat; trouble breathing, swallowing, or talking; unusual hoarseness; or swelling of the mouth, face, lips, tongue, or throat.
- Signs of depression, thoughts of suicide, nervousness, emotional ups and downs, thinking that is not normal, anxiety, or lack of interest in life.
- Hallucinations (seeing or hearing things that are not there).
- Feeling confused, not able to focus, or change in behavior.
- A change in weight without trying.
- Appetite changes.
- Sleepwalking.
- Trouble breathing, slow breathing, or shallow breathing.

Sodium Oxybate 5/12

- Breathing problems during sleep (sleep apnea).
- Severe dizziness or passing out.

What are some other side effects of this drug?

All drugs may cause side effects. However, many people have no side effects or only have minor side effects. Call your child's doctor or get medical help if any of these side effects or any other side effects bother your child or do not go away:

- Dizziness.
- Upset stomach or throwing up.
- Bedwetting.
- Shakiness.
- Headache.
- Abnormal dreams, sleep talking, or other abnormal effects during sleep.

These are not all of the side effects that may occur. If you have questions about side effects, call your child's doctor. Call your child's doctor for medical advice about side effects.

You may report side effects to your national health agency.

Sodium Oxybate 6/12

How is this drug best given?

Give this drug as ordered by your child's doctor. Read all information given to you. Follow all instructions closely.

Solution:

- Give 2 doses each night.
- Give on an empty stomach. Give the first dose at least 2 hours after eating.
- This drug needs to be mixed before use. Follow how to mix as you were told by the doctor.
- Measure liquid doses carefully. Use the measuring device that comes with this drug.
- Use within 24 hours after you mix this drug.
- Prepare each dose before your child goes to bed.
- Store prepared doses in the child-resistant dosing containers in a safe place.
- Have your child lie down right away and stay in bed after taking doses.
- Give the first dose at bedtime after your child gets into bed.
- Space doses by at least 2.5 to 4 hours.
- Set alarm clock to wake up for second dose.

Sodium Oxybate 7/12

Powder for suspension:

- Give this drug at bedtime at least 2 hours after your child eats.
- Mix this drug in the cup provided. Put the amount needed for your child's dose in about 1/3 cup (80 mL) of water. You may add calorie-free drink mix or flavored water enhancer. Do not use hot water. Put the cap on the cup and shake well for at least 60 seconds. Give this drug within 30 minutes after mixing.
- After giving your child's dose, add more water to the cup. Put the cap on the cup and shake well for at least 10 seconds. Have your child drink to be sure the whole dose is given.
- Give while your child is in bed and have your child lie down right away. Have your child stay in bed after taking this drug.

What do I do if my child misses a dose? Solution:

- If your child misses the second dose, skip the missed dose. Do not give another dose until the next night.
- Do not give 2 doses at the same time or extra doses.

Sodium Oxybate 8/12

Powder for suspension:

- Skip the missed dose. Do not give another dose until the next day at bedtime.
- Do not give 2 doses at the same time or extra doses.

How do I store and/or throw out this drug?

- Before mixing, store in the original container.
- Store at room temperature in a dry place. Do not store in a bathroom.
- Store this drug in a safe place where children cannot see or reach it, and where other people cannot get to it. A locked box or area may help keep this drug safe. Keep all drugs away from pets.
- Throw away unused or expired drugs. Do not flush down a toilet or pour down a drain unless you are told to do so. Check with your pharmacist if you have questions about the best way to throw out drugs. There may be drug take-back programs in your area.

General drug facts

- If your child's symptoms or health problems do not get better or if they become worse, call your child's doctor.
- Do not share your child's drug with others and do not give anyone else's drug to your child.

Sodium Oxybate 9/12

- Some drugs may have another patient information leaflet. If you have any questions about this drug, please talk with your child's doctor, nurse, pharmacist, or other health care provider.
- If you think there has been an overdose, call your poison control center or get medical care right away. Be ready to tell or show what was taken, how much, and when it happened.

Consumer Information Use and Disclaimer

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Sodium Oxybate 10/12

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Sodium Oxybate 11/12

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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Sodium Oxybate 12/12