PATIENT & CAREGIVER EDUCATION

Cysteamine (Systemic

This information from UpToDate® Lexidrug™ 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

Cystagon; Procysbi

Brand Names: Canada

Procysbi

What is this drug used for?

- It is used to treat nephropathic cystinosis.

What do I need to tell my doctor BEFORE I take this drug?

- If you are allergic to this drug; any part of this drug; or any other drugs, foods, or substances. Tell your doctor about the allergy and what signs you had.
- If you are breast-feeding. Do not breast-feed while you take this drug.

This drug may interact with other drugs or health problems.

Tell your doctor and pharmacist about all of your drugs (prescription or OTC, natural products, vitamins) and health problems. You must check to make sure that it is safe for you to take this drug with all of your drugs and health problems. Do not start, stop, or change the dose of any drug without checking with your doctor.

What are some things I need to know or do while I take this drug?

For all patients taking this drug:

- Tell all of your health care providers that you take this drug. This includes your doctors, nurses, pharmacists, and dentists.
- Avoid driving and doing other tasks or actions that call for you to be alert until you see how this drug affects you.
- Have your blood work and other lab tests checked as you have been told by your doctor.
- Avoid drinking alcohol while taking this drug.
- This drug may raise the chance of ulcers or bleeding from the stomach or bowel. Talk with the doctor.
- If you are pregnant or you get pregnant while taking this drug, call your doctor right away.

Children:

- If your child's weight changes, talk with the doctor. The dose of this drug may need to be changed.

What are some side effects that I need to call my 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 doctor or get medical help right away if you have any of the following signs or symptoms that may be related to a very bad side effect:

All products:

- 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 fluid and electrolyte problems like mood changes, confusion, muscle pain or weakness, fast or abnormal heartbeat, severe dizziness or passing out, increased thirst, seizures, feeling very tired or weak, decreased appetite, unable to pass urine or change in the amount of urine produced, dry mouth, dry eyes, or severe upset stomach or throwing up.
- Ringing in ears.
- Dizziness or passing out.
- Feeling sleepy.
- Eye pain.
- Stomach pain; black, tarry, or bloody stools; throwing up blood; or throw up that looks like coffee grounds.
- Upset stomach or throwing up.
- Decreased appetite.
- Depression.
- Low white blood cell counts have happened with this drug. This may lead to a higher chance of getting an infection. Call your doctor right away if you have signs of infection like fever, chills, or sore throat.
- A very bad skin reaction (toxic epidermal necrolysis) may happen. It can cause very bad health problems that may not go away, and sometimes death. Get medical help right away if you have signs like red, swollen, blistered, or peeling skin (with or without fever); red or irritated eyes; or sores in your mouth, throat, nose, or eyes.
- Raised pressure in the brain has happened with this drug. Most of the time, this will go back to normal after this drug is stopped. Sometimes, loss of eyesight may happen and may not go away even after this drug is stopped. Call your doctor right away if you have a headache or eyesight problems like blurred eyesight, seeing double, or loss of eyesight.
- Very bad skin problems like stretch marks, joint problems, and bone problems like broken bones and deformed bones have happened with this

drug. Call your doctor right away if you have any skin changes or bone or joint pain.

All delayed-release products:

- A severe bowel problem called fibrosing colonopathy has happened with this drug. Call your doctor right away if you have stomach pain, throwing up, weight loss, bloody or long-lasting diarrhea, or are not able to control bowel movements.

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 doctor or get medical help if any of these side effects or any other side effects bother you or do not go away:

- Diarrhea.
- Feeling tired or weak.
- Change in body odor.
- Bad breath.
- Eye irritation.
- Flu-like signs.
- Nose or throat irritation.
- Ear pain.

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

You may report side effects to your national health agency.

You may report side effects to the FDA at 1-800-332-1088. You may also report side effects at https://www.fda.gov/medwatch.

How is this drug best taken?

Use this drug as ordered by your doctor. Read all information given to you. Follow all instructions closely.

Immediate-release capsules:

- Swallow whole. Do not chew or crush.
- You may sprinkle contents of capsule on food.
- Keep taking this drug as you have been told by your doctor or other health care provider, even if you feel well.

Delayed-release capsules:

- Swallow whole. Do not chew or crush.
- Take this drug with fruit juice (not grapefruit juice) or water.
- You may sprinkle contents of capsule on up to 1/2 cup (4 ounces/120 mL) of applesauce or berry jelly. The contents may also be mixed in 1/2 cup (4 ounces/120 mL) of fruit juice (not grapefruit juice). Do not chew. Take within 30 minutes of mixing.

Delayed-release granules:

- Sprinkle granules on up to 1/2 cup (4 ounces or 120 mL) of applesauce or berry jelly. May also be mixed in 1/2 cup (4 ounces or 120 mL) of fruit juice (not grapefruit juice). Do not crush or chew granules. Take within 30 minutes of mixing.

All delayed-release products:

- Keep taking this drug as you have been told by your doctor or other health care provider, even if you feel well.
- Take at least 30 minutes before or 2 hours after a meal.
- If you cannot take this drug without eating, you can eat a little bit of food (about 1/2 cup) within 1 hour before taking this drug through 1 hour after taking it.

- Always take with a little bit of food or always take on an empty stomach.
- Avoid high-fat food close to when you take this drug.
- Those who have feeding tubes may use this drug. Use as you have been told. Flush the feeding tube after this drug is given.
- If you take other drugs, they may need to be taken at a different time than this drug. Check with your doctor or pharmacist about the best time to take them.

What do I do if I miss a dose?

Immediate-release capsules:

- Take a missed dose as soon as you think about it.
- If it is less than 2 hours until your next dose, skip the missed dose and go back to your normal time.
- Do not take 2 doses at the same time or extra doses.

All delayed-release products:

- Take a missed dose as soon as you think about it.
- If the next dose is less than 4 hours away, skip the missed dose and go back to your normal time.
- Do not take 2 doses at the same time or extra doses.

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

All products:

- Store at room temperature protected from light. Store in a dry place. Do not store in a bathroom.
- Keep all drugs in a safe place. Keep all drugs out of the reach of children and 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.

Delayed-release capsules:

- Store in the original container. Do not take out the antimoisture cube or packet.
- Keep lid tightly closed.

Delayed-release granules:

- Do not open until you are ready to use.
- Throw away any part of the opened packet after the dose is given. Do not store opened packets for future use.

General drug facts

- If your symptoms or health problems do not get better or if they become worse, call your doctor.
- Do not share your drugs with others and do not take anyone else's drugs.
- Some drugs may have another patient information leaflet. If you have any questions about this drug, please talk with your doctor, nurse, pharmacist, or other health care provider.
- Some drugs may have another patient information leaflet. Check with your pharmacist. If you have any questions about this drug, please talk with your 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

This generalized information is a limited summary of diagnosis, treatment, and/or medication information. It is not meant to be comprehensive and should be used as a tool to help the user understand and/or assess potential diagnostic and treatment options. It does NOT include all information about conditions,

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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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