Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

Inotersen

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

Tegsedi [DSC]

Brand Names: Canada

Tegsedi [DSC]

Warning

- This drug can cause low platelet levels. Sometimes, very low platelet levels have led to life-threatening or deadly bleeding problems. If you have questions, talk with the doctor.
- If you have a low platelet count, talk with your doctor.
- Have your blood work and other lab tests checked as you have been told by your doctor.

- Call your doctor right away if you have any signs of bleeding problems, like bruising; black, tarry, or bloody stools; bleeding gums; blood in the urine; coughing up blood; cuts that take a long time to stop bleeding; feel dizzy; feeling very tired or weak; nosebleeds; pain or swelling; throwing up blood or throw up that looks like coffee grounds; or very bad headache.
- Kidney problems have happened with this drug. Sometimes, people have needed dialysis. Kidney problems may be long-lasting. If you have questions, talk with the doctor.
- If you have kidney disease, talk to your doctor.
- Call your doctor right away if you have signs of kidney problems like not able to pass urine; change in how much urine is passed; bloody, brown, or foamy urine; shortness of breath or cough; or puffy or swollen face, feet, or hands.

What is this drug used for?

- It is used to treat nerve problems in people with amyloidosis.

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 have low platelet levels.
- If you have had kidney problems caused by this drug.

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

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?

- Tell all of your health care providers that you take this drug. This includes your doctors, nurses, pharmacists, and dentists.
- Allergic reactions have happened with this drug. Most of the time, these reactions happened within 2 hours after a dose. Call your doctor right away if you have chest pain; chills; flu-like signs; flushing; muscle or joint pain;

not able to control body movements; redness of the palms of hands; signs of high blood pressure like very bad headache or dizziness, passing out, or change in eyesight; trouble swallowing; or any other bad effects.

- You may need to take vitamin A while taking this drug. Be sure to follow what your doctor has told you.
- This drug may affect certain lab tests. Tell all of your health care providers and lab workers that you take this drug.
- You may bleed more easily. Be careful and avoid injury. Use a soft toothbrush and an electric razor.
- Liver problems have happened with this drug. In people who have had a liver transplant, rejection of the liver has happened. If you have liver problems or have had a liver transplant, talk with your doctor.
- If you are 65 or older, use this drug with care. You could have more side effects.
- Tell your doctor if you are pregnant, plan on getting pregnant, or are breast-feeding. You will need to talk about the benefits and risks to you and the baby.
- Do not take more vitamin A than what your doctor told you to take. Taking too much vitamin A during pregnancy may cause birth defects. If you have questions, talk with your doctor.

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:

- 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 liver problems like dark urine, tiredness, decreased appetite, upset stomach or stomach pain, light-colored stools, throwing up, or yellow skin or eyes.
- Feeling confused.
- Stiff neck.
- Trouble walking.
- Muscle pain or weakness.
- Muscle spasm.
- Back pain.
- Weight loss.
- Swelling in the arms or legs.

- Fast, slow, or abnormal heartbeat.
- A burning, numbness, or tingling feeling that is not normal.
- Shortness of breath.
- Severe dizziness or passing out.
- Change in eyesight like trouble seeing at night.
- Rarely, stroke and carotid artery problems happened in patients taking this drug. Tell your doctor right away if you have severe headache; face, eye, or neck pain; weakness on 1 side of the body; trouble speaking or thinking; change in balance; drooping on 1 side of the face; blurred eyesight; or confusion.

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:

- Pain, redness, swelling, or other reaction where the injection was given.
- Upset stomach or throwing up.
- Headache.
- Feeling tired or weak.

- Fever.
- Decreased appetite.
- Dry mouth.

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.

- It is given as a shot into the fatty part of the skin on the top of the thigh or the belly area.
- This drug may be given into the outer area of the upper arm if given by someone else.
- If you will be giving yourself the shot, your doctor or nurse will teach you how to give the shot.
- Take the same day each week.

- Move the site where you give the shot with each shot.
- If stored in a refrigerator, let this drug come to room temperature before using it. Leave it at room temperature for at least 30 minutes. Do not heat this drug.
- Do not give into skin within 2 inches (5 cm) of the belly button.
- Do not inject at the waistline or in any other area where pressure or rubbing from clothes can happen.
- Do not give into tender, bruised, red, or hard skin.
- Do not give into skin that is tattooed or scarred.
- Do not use if the solution is cloudy, leaking, or has particles.
- This drug is colorless to a faint yellow. Do not use if the solution changes color.
- Each prefilled syringe is for one use only.
- Throw away needles in a needle/sharp disposal box. Do not reuse needles or other items. When the box is full, follow all local rules for getting rid of it. Talk with a doctor or pharmacist if you have any questions.

What do I do if I miss a dose?

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

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

- Store in a refrigerator. Do not freeze.
- Store in the original container to protect from light.
- If you drop this drug on a hard surface, do not use it.
- If needed, you may store at room temperature for up to 6 weeks. If stored at room temperature and not used within 6 weeks, throw this drug away.
- Protect from heat. Do not leave this drug at temperatures above 86°F (30°C).
- 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.

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.
- This drug comes with an extra patient fact sheet called a Medication Guide. Read it with care. Read it again each time this drug is refilled. If you have any questions about this drug, please talk with the doctor, 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, treatments, medications, side effects, or risks that may apply to a specific patient. It is not intended to be medical advice or a substitute for the medical advice, diagnosis, or treatment of a health care provider based on the health care provider's examination and assessment of a patient's specific and unique circumstances. Patients must speak with a health care provider for complete information about their health, medical questions, and treatment options, including any risks or benefits regarding use of medications. This information does not endorse any treatments or medications as safe, effective, or approved for treating a specific patient. UpToDate, Inc. and its affiliates disclaim any warranty or liability relating to this information or the use thereof. The use of this information is governed by the Terms of Use, available at https://www.wolterskluwer.com/en/know/clinical-effectiveness-terms.

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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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