

# Nirogacestat

**Care Team Contact Information:** \_\_\_\_\_

**Pharmacy Contact Information:** \_\_\_\_\_

**Diagnosis:** \_\_\_\_\_

- This treatment is often used for desmoid tumors, but it may also be used for other diagnoses.

**Goal of Treatment:** \_\_\_\_\_

- Treatment may continue until it no longer works or until side effects are no longer controlled.

## Treatment Regimen

Treatment Name	How the Treatment Works	How the Treatment is Given
Nirogacestat (NY-roh-GAY-seh-stat): Ogsiveo (og-SIH-vee-oh)	Slows down or stops the growth of cancer cells by blocking a specific protein that helps them survive.	Tablet taken by mouth.

## Treatment Administration and Schedule

Your nirogacestat dosing instructions:

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- Nirogacestat comes in 2 tablet strengths: 100 mg and 150 mg. Each strength is supplied in blister packs.
- Take nirogacestat 2 times a day with or without food. Take nirogacestat at around the same times each day.
- Swallow nirogacestat tablets whole. Do not break, crush, or chew tablets.
- If you take an antacid medicine, take nirogacestat 2 hours before or 2 hours after taking the antacid.
- If you vomit after taking a dose or miss a dose of nirogacestat, take your next dose at your regular time. Do not take 2 doses of nirogacestat to make up the dose.

## Storage and Handling of Nirogacestat

- Store nirogacestat tablets at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep nirogacestat and all medicines out of the reach of children and pets.
- Ask your care team how to safely throw away any unused nirogacestat.

**Appointments:** Appointments may include regular check-ups with your care team, lab visits, and imaging tests. It's important to keep your appointments whenever you can. If you miss any appointments, call your care provider as soon as possible to reschedule your appointment

**Supportive Care to Prevent and Treat Side Effects**

Description	Supportive Care Taken at Home
To help prevent or treat nausea and vomiting	<hr/> <hr/>
Other	<hr/> <hr/>

**Common Side Effects**

Side Effect	Important Information
Nausea and Vomiting	<p>Description: Nausea is an uncomfortable feeling in your stomach or the need to throw up. This may or may not cause vomiting.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>• Eat smaller, more frequent meals.</li> <li>• Avoid fatty, fried, spicy, or highly sweet foods.</li> <li>• Eat bland foods at room temperature and drink clear liquids.</li> <li>• If you vomit, start with small amounts of water, broth, or other clear liquids when you are ready to eat again. If that stays down, then try soft foods (such as gelatin, plain cornstarch pudding, yogurt, strained soup, or strained cooked cereal). Slowly work up to eating solid food.</li> <li>• Your care team may prescribe medicine for these symptoms.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• Vomiting for more than 24 hours</li> <li>• Vomiting that's nonstop</li> <li>• Signs of dehydration (like feeling very thirsty, having a dry mouth, feeling dizzy, or having dark urine)</li> <li>• Blood or coffee-ground-like appearance in your vomit</li> <li>• Bad stomach pain that doesn't go away after vomiting</li> </ul>
Mouth Irritation and Sores	<p>Description: This treatment can irritate the lining of the mouth. In some cases, this can cause redness, sores, pain, and swelling.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>• Rinse your mouth after meals and at bedtime, and more often if sores develop.</li> <li>• Brush your teeth with a soft toothbrush or cotton swab after meals.</li> <li>• Use a mild, non-alcohol mouth rinse at least four times daily (after meals and at bedtime). A simple mixture is 1/8 teaspoon salt and 1/4 teaspoon baking soda in 8 ounces of warm water.</li> <li>• Avoid acidic, hot, spicy, or rough foods and drinks that may irritate your mouth.</li> <li>• Avoid tobacco, alcohol, and alcohol-based mouthwashes.</li> <li>• Your care team may prescribe medicine for these symptoms.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• Pain or sores in your mouth or throat</li> </ul>

<p>Diarrhea</p>	<p>Description: Diarrhea is when you have loose, watery bowel movements more often than usual. The need to use the bathroom may occur urgently.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>• Keep track of how many times you go to the bathroom each day.</li> <li>• Drink 8 to 10 glasses of water or other fluids every day, unless your care team tells you otherwise.</li> <li>• Eat small meals of mild, low-fiber foods like bananas, applesauce, potatoes, chicken, rice, and toast.</li> <li>• Avoid eating foods with high fiber (like raw vegetables, fruits, and whole grains), foods that cause gas (like broccoli and beans), dairy foods (like yogurt and milk), and spicy, fried, and greasy foods.</li> <li>• Your care team may recommend medicine (such as loperamide) for diarrhea.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• 4 or more bowel movements than normal in 24 hours</li> <li>• Dizziness or lightheadedness while having diarrhea</li> <li>• Bloody diarrhea</li> </ul>
<p>Liver Problems</p>	<p>Description: Treatment can harm your liver. This may cause nausea, stomach pain, and bleeding or bruising. It can also turn your skin and eyes yellow and make your urine dark. Lab tests may be performed to monitor liver function.</p> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• Yellowing of your skin or the whites of your eyes</li> <li>• Severe nausea or vomiting</li> <li>• Pain on the right side of your stomach area (abdomen)</li> <li>• Dark urine (tea colored)</li> <li>• Bleeding or bruising more easily than normal</li> </ul>
<p>Ovarian Problems</p>	<p>Description: People who are able to become pregnant may have ovarian problems and changes in their menstrual cycle during treatment with nirogacestat. Nirogacestat may affect fertility which may affect your ability to have a child.</p> <p>Talke to your care team if you have:</p> <ul style="list-style-type: none"> <li>• Changes in your menstrual cycle</li> <li>• Hot flashes</li> <li>• Night sweats</li> <li>• Vaginal dryness</li> </ul>

<p>Rash or Itchy Skin</p>	<p>Description: Treatment can cause a rash with itchy, dry, red, or puffy skin.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>• Take a warm (not hot) bath or shower every day with mild, unscented soap or body wash.</li> <li>• Pat skin dry (instead of rubbing) with a towel.</li> <li>• Use unscented lotion or moisturizing cream immediately after showering to prevent cracking.</li> <li>• Use lip balm for dry or chapped lips.</li> <li>• Avoid activities that put you at risk for cuts, injuries or burns.</li> <li>• Use an electric shaver, not a razor, to prevent cuts.</li> <li>• Rinse cuts and scrapes immediately under running water and remove any debris from the wound. Wash the skin around the wound with soap. To avoid irritation, do not use soap on the wound. If you have a low platelet count and are at risk for bleeding issues, ask your doctor how to care for cuts.</li> <li>• Avoid direct sun when possible. Wear a broad-spectrum sunscreen with SPF 30 or higher and reapply every 2 hours.</li> <li>• Use unscented, gentle laundry detergent. Some laundry detergents can irritate sensitive skin.</li> <li>• Your care team may recommend medicine for skin problems.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• Skin rash</li> <li>• Raised red bumps</li> <li>• Redness of the skin</li> <li>• Very dry skin that may affect the mucous membranes (such as mouth and eyes)</li> </ul>
<p>Headache</p>	<p>Description: A headache can cause you to feel pain or discomfort in your head, making it hard to concentrate or feel your best.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>• Keep a headache diary to track the frequency, duration, intensity, and triggers of your headaches.</li> <li>• Stay hydrated by drinking plenty of water, as dehydration can contribute to headaches.</li> <li>• Apply a cold or warm compress to your forehead or neck to help ease headache pain.</li> <li>• Get adequate sleep (7-8 hours per night) and establish a regular sleep schedule.</li> <li>• Limit caffeine intake.</li> <li>• Your care team may recommend medicine for headaches.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• Severe headache</li> <li>• More frequent headaches</li> <li>• Dizziness or light-headedness</li> <li>• Confusion</li> <li>• Vision changes</li> </ul>

<p>Electrolyte (Salt) Problems</p>	<p>Description: Your care team will do blood tests to check your phosphate and potassium levels during treatment.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Your care team may give you medicine to treat low phosphate or low potassium if needed.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Muscle pain or weakness</li> </ul>
<p>Fatigue</p>	<p>Description: Fatigue is a constant and sometimes strong feeling of tiredness.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Routine exercise has been shown to decrease levels of fatigue. Work with your care team to find the right type of exercise for you.</li> <li>Ask your family and friends for help with daily tasks and emotional support.</li> <li>Try healthy ways to feel better, like meditation, writing in a journal, doing yoga, and using guided imagery to lower anxiety and feel good.</li> <li>Make a regular sleep schedule and limit naps during the day so you can sleep better at night, aiming for 7 to 8 hours of sleep.</li> <li>Don't use heavy machines or do things that need your full attention if you're very tired to avoid accidents.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Tiredness that affects your daily life</li> <li>Tiredness all the time, and it doesn't get better with rest</li> <li>Dizziness and weakness, along with being tired</li> </ul>

**Select Rare Side Effects**

Side Effect	Talk to Your Care Team if You Have Any of These Signs or Symptoms
<p>New Non-Melanoma Skin Cancers</p>	<p>Your care team may do skin exams before and during treatment if you are at risk for skin cancer.</p> <ul style="list-style-type: none"> <li>New or changing skin lesions</li> </ul>

**Before starting treatment, ask your care team when to call 9-1-1 or seek emergency help. If you experience any new, worsening, or uncontrolled side effects, contact your care team immediately.**

**Intimacy, Fertility, Pregnancy, and Breastfeeding**

- Treatment may **change how you feel about intimacy and your body**. However, physical closeness—such as holding hands and hugging—remains safe. It is common to have questions about intimacy. If needed, talk to your care team for guidance.
- Treatment can affect your **ability to have children**. It may damage your reproductive organs or stop them from working. If you are worried about fertility, talk to your care team before starting treatment.
- Treatment may **harm an unborn baby**.
  - If you are able to become pregnant, take a pregnancy test before starting treatment.
  - Use an effective method of birth control during treatment and for 1 week after your last dose.
  - If you think you might be pregnant or if you become pregnant, tell your care team right away.
  - If your partner(s) could become pregnant, use an effective method of birth control—such as condoms—during treatment and for 1 week after your last dose.
- **Do NOT breastfeed** during treatment and for 1 week after your last dose.

**Additional Information**

- **Tell your care team about all the medicines you take.**  
This includes prescriptions, over-the-counter drugs, vitamins, and herbal products. Before starting any new medicine, supplement, or vaccine, ask your care team first.
- You should **avoid taking proton pump inhibitors (PPIs)** (like omeprazole and esomeprazole) **and H2 blockers** (like famotidine) during treatment with nirogacestat. If you take an antacid medicine, take nirogacestat 2 hours before or 2 hours after taking the antacid.
- **Avoid eating or drinking grapefruit products, Seville oranges (often used in marmalades), and starfruit** during treatment with nirogacestat. These products may increase the amount of nirogacestat in your blood.
- **This Patient Education Sheet may not describe all possible side effects.**  
Call your healthcare provider for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

**Notes**

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Scan the QR code below to access this education sheet.



Important notice: The Association of Cancer Care Centers (ACCC), Hematology/Oncology Pharmacy Association (HOPA), Network for Collaborative Oncology Development & Advancement, Inc. (NCODA), and Oncology Nursing Society (ONS) have collaborated in gathering information for and developing this patient education guide. This guide represents a brief summary of the medication derived from information provided by the drug manufacturer and other resources.

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