

Tocilizumab

Care Team Contact Information: _____

Pharmacy Contact Information: _____

Diagnosis: _____

- This treatment is used for cytokine release syndrome (CRS), a serious immune reaction caused by chimeric antigen receptor (CAR) T-cell therapy.
- It may also be used for other reasons.

Goal of Treatment: _____

Treatment Regimen

Treatment Name	How the Treatment Works	How the Treatment is Given
Tocilizumab (toh-sih-LIH-zoo-mab): Actemra (ak-TEM-ruh), Avtozma, Tofidence, Tyenne	Blocks a protein in the immune system that causes inflammation.	Infusion into a vein (intravenous (IV) infusion).

Treatment Administration and Schedule

Treatment is typically given once. However, if there is no improvement in the signs and symptoms of CRS after the first dose, up to 3 more doses may be given (up to 4 total doses).

Appointments

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

Supportive Care to Prevent and Treat Side Effects

Description	Supportive Care Given at the Clinic or Hospital	Supportive Care Taken at Home
Supportive care used to treat or prevent side effects		

Select Rare Side Effects

Side Effect	Talk to Your Care Team if You Have Any of These Signs or Symptoms	
Low White Blood Cell (WBC) Count (Neutropenia) and Increased Risk of Infection (Boxed Warning)	WBCs help protect your body from infections. A low WBC count increases your risk of infection. Some infections can be serious or life-threatening. Your care team will perform blood tests to check your WBC count and may test you for tuberculosis (TB) before you start treatment. - Fever of 100.4 °F (38°C) or higher - Chills - Burning and painful urination - Urinating often - Weakness and tiredness - Coughing up yellow or pink mucus (phlegm)	
Low Platelet Count (Thrombocytopenia)	- Bruising easily - Frequent nose bleeds - Blood in your urine or stool - Blood in your spit after a cough	
Herpes Zoster (Shingles and Chickenpox Virus) Reactivation	- Fever or chills - Headache or feeling very tired - Eye pain, vision changes, or a rash near your eye - Fever or chills - Headache or feeling very tired - Eye pain, vision changes, or a rash near your eye	
Worsening Neurologic Problems	Treatment can cause worsening of serious neurologic (brain and nerve) problems that can be life-threatening and may lead to death. These problems can include a condition called Immune Effector Cell-Associated Neurotoxicity Syndrome (ICANS). Neurologic problems may occur days or weeks after treatment. Your care team may refer you to a specialist who treats neurologic problems. If you develop neurologic side effects, do not drive or operate dangerous machinery until your care team says it is safe. - Headache - Agitation, trouble staying awake, confusion or disorientation, seeing or hearing things that are not real (hallucinations) - Trouble speaking, writing, thinking, remembering things, paying attention, or understanding things - Problems walking, muscle weakness, shaking (tremors), loss of balance, or muscle spasms - Numbness and tingling (feeling like ""pins and needles"") - Burning, throbbing, or stabbing pain - Changes in your handwriting - Seizures	
Tears in Your Stomach or Intestines (Gastrointestinal Perforation)	Gastrointestinal perforation may be severe and lead to death. Tell your care team right away if you develop any of the following signs or symptoms: - Tenderness or pain in your stomach area (abdomen) that is severe or does not go away - Nausea, vomiting, or vomiting blood - Blood in the stool or black stool that looks like tar - Fever or chills	

Allergic Reactions, Including Anaphylaxis	Get emergency medical help right away if you develop any of the following signs or symptoms: • Swelling of your lips, mouth, tongue, or throat • Trouble breathing or swallowing • Raised red areas on your skin (hives) • A very fast heartbeat • You feel dizzy or faint
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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, 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 may **harm an unborn baby**.
 - If you are able to become pregnant:
 - Your care team will verify your pregnancy status before treatment.
 - Use an effective method of birth control during treatment with tocilizumab.
 - If you think you might be pregnant or if you become pregnant, tell your care team right away.
 - If your partner is able to become pregnant, use an effective method of birth control—such as condoms—during treatment with tocilizumab.
- It is **not known** if tocilizumab is present in **breast milk**. Talk with your care team if you are breastfeeding or plan to breastfeed.

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 not receive a “live vaccine”** before, during, or after treatment, until your care team tells you it is okay. If you are not sure about the type of immunization or vaccine, ask your care team. These vaccines may not be safe or may not work as well during treatment.
- **This Patient Education Sheet may not describe all possible side effects.**
 Call your care team 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 to gather information and develop this patient education guide. This guide is a summary of the medication, based on information provided by the drug manufacturer and other sources.

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